



**Holding pieces of the same puzzle:
using an understanding of the prevalence and impact of adverse
childhood experiences (ACEs) to target mental health resources**

Katherine Lyndsey Parkin

Pembroke College
Department of Public Health and Primary Care
University of Cambridge

This thesis is submitted for the degree of Doctor of Philosophy
September 2024

Declaration

This thesis is the result of my own work and includes nothing which is the outcome of work done in collaboration except as declared in the preface and specified in the text. It is not substantially the same as any work that has already been submitted, or is being concurrently submitted, for any degree, diploma or other qualification at the University of Cambridge or any other University or similar institution except as declared in the preface and specified in the text. It does not exceed the prescribed word limit for the relevant Degree Committee.

Abstract

Introduction: Adverse childhood experiences (ACEs) are known to be associated with poor mental health outcomes. This thesis seeks to understand the extent to which different ACEs can be measured using routinely-collected data, and what early interventions might be indicated to support the mental health of young people who experience them.

Methods: The thesis comprises a rapid literature review and survey of experts to understand mental health risk factors, measurement of ACEs in a databank of routinely-collected linked data from young people, and an umbrella review of prevention and early intervention strategies to support young people's mental health following exposure to ACEs.

Results: In brief, the three studies demonstrate that: 1) experts believe ACEs are important risk factors for predicting mental health problems earlier in young people; 2) some, though not all types of ACEs can to a variable extent be measured in routinely-collected linked health and social care data, yet this is currently a time-intensive and costly process, with various limitations including the crucial fact that it clearly misses many cases of ACEs; and 3) there is evidence supporting that early interventions are effective for mitigating poor mental health outcomes following exposure to certain ACEs.

Conclusions: Measurement of ACEs using routine data sources is a potential mechanism by which young people could be identified and offered earlier interventions for those who need them. There remains a long way to go before this could be a routine practice and, at present, measurement of ACEs would need to be heavily supplemented by other approaches to ensure measurement gaps are addressed. However, ACE-informed decision-making and resource allocation could be a valuable approach to explore in order to proactively support the mental health of young people, shifting the dial away from late treatment and towards timely and proportionate prevention and support.



Measuring Adverse Childhood Experiences (ACEs) through linked data to improve young people's mental health

The Problem

Adverse Childhood Experiences (or ACEs) are an important predictor of mental health problems. If young people are identified and supported earlier, their mental health outcomes in childhood and beyond could be improved.

Research Questions

To what extent is it possible to measure different ACEs using routinely-collected data?

What can be done to mitigate any negative mental health impacts for young people who experience different ACEs?

The Research

1

Rapid literature review and survey of experts to identify key risk factors for mental health problems.



2

Linkage of routinely-collected data (demographics, healthcare and social care) to measure ACEs.



3

Umbrella review of 82 systematic reviews to find early interventions for mental health after ACEs.



Key Results

Risk factor framework created to inform early identification tools.

51 out of 287 risk factors were ACEs.

Mental health experts saw ACEs as important for earlier prediction.



Most ACE types measurable in routinely-collected data. Some not e.g. bullying, racism, community violence.

Linking data from different agencies increased amount of ACEs measured.



Literature revealed many effective early interventions after ACE exposure.

Some interventions much less documented than others e.g. parental imprisonment, separation, or death.



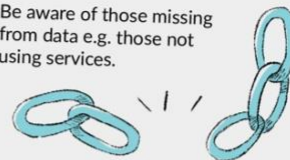
Recommendations

Early identification tools need developing and testing.
Invest in young people's mental health in an ACE-informed way.



Recognise the power of linked data.

Be aware of those missing from data e.g. those not using services.



Prioritise prevention and early intervention over late treatment.

Early identification tools could detect those in need of support.



UNIVERSITY OF
CAMBRIDGE

To read the PhD thesis behind this infographic, visit:
researchgate.net/profile/Katherine-Parkin-3

Funded by:

NIHR | School for Public Health Research

NIHR | Applied Research Collaboration East of England



Research supported by:



Credit: designed by Nifty Fox Creative, 2024.

Dedicated to the Child As of the world, and the often forgotten Child Bs too.

(‘Boy A’ – Jonathan Trigell)

Acknowledgements

A whole host of people and organisations helped to make this PhD what it is... Firstly, I'd like to thank my PhD co-funders – NIHR SPHR and NIHR ARC EoE – without whom I would not have been able to spend three years learning and exploring these topics. In addition, thank you to WWCSC, CPFT and the MRC who provided additional project-specific funding. A huge thanks to my supervisory team, Dr Anna Moore and Prof. Carol Brayne, whose support, guidance and expertise were invaluable in shaping the project, and Dr Louise Lafortune for being there as a caring advisor whenever I needed her. Thank you also to the rest of the Timely team over the years for their amazing support and research insights – Rachel, Ryan, Bianka, Lina, Alisa, Shabina, Sowmiya, Julian, Kate, and our brilliant placement students, Yi, Emily, Charlotte, Tara, Vahgisha and Olivia. In addition, thanks to everyone who contributed to individual studies (as highlighted in each chapter Declaration section). And to the support staff who helped things feel seamless when they were probably anything but...Andi, Katia, Judith, thank you!

Thank you to my lovely coursemates, department colleagues (especially Ledia and Joyce), friends and housemates, who made the last few years an absolute blast. I'd also like to thank my family, with a special mention to my amazing mum, Dianne, who knew I'd want to do a PhD years before I knew it myself. Your curiosity and love of learning has inspired me to constantly ask questions (for better or worse!). And a shoutout to the proofreading and formatting dream team – my mum, Alex, and Chris – who helped me finesse this thesis. In addition, I'd like to acknowledge the communities I've never met but have helped me immeasurably throughout the PhD, including data providers and patients, W3Schools, Stack Overflow and R communities, Flourish team, and the musicians who were the soundtrack to my thesis. Thanks also to Nifty Fox Creative, who brought the final thesis to life in colour and images.

And a final acknowledgement to the places, spaces and context that were the backdrop to this work. It may be a little strange, but I guess if you can acknowledge places and spaces anywhere, a Public Health PhD feels like the right place! Some of my best writing was done on public transport, on buses or trains to the department and office respectively, with the time-bound, WiFi-free moments creating the headspace needed to write. The University and city of Cambridge also continually inspired me, being places that are rich in ideas and history, and where I felt grateful to be every day. And though it certainly had huge downsides, I'd also like to acknowledge the contribution of the COVID-19 pandemic which prompted me to spend a summer writing a PhD funding application in a park, facilitated co-working online with friends I'd probably never have made otherwise, and made me grateful for the privilege of being paid to learn!

Funding and Disclaimers

My PhD was co-funded by the National Institute for Health and Care Research (NIHR) School for Public Health Research (SPHR) (Grant Reference Number PD-SPH-2015) and the NIHR Applied Research Collaboration East of England (ARC EoE) at Cambridgeshire and Peterborough NHS Foundation Trust.

Additional funding was provided for specific projects. The Delphi Study was funded by a Medical Research Council award to Dr Moore (MRC Adolescent Engagement Awards MR/T046430/1). The work in the SAIL Databank was co-funded by a What Works for Children's Social Care (WWCSC) Spark Grant and funding from Cambridgeshire and Peterborough NHS Foundation Trust (CPFT), awarded to Dr Moore. The work in SAIL was also supported by the Adolescent Mental Health Data Platform (ADP). The ADP is funded by MQ Mental Health Research Charity (Grant Reference MQBF/3 ADP).

The views expressed in this thesis are my own and not necessarily those of the NIHR, the Department of Health and Social Care, the MRC, WWCSC, CPFT, the ADP or MQ Mental Health Research Charity.

Manuscripts Arising from Work During this PhD

1. Moorthie, S., Hayat, S., Zhang, Y., **Parkin, K.**, Philips, V., Bale, A., Duschinsky, R., Ford, T., & Moore, A. (2022). Rapid systematic review to identify key barriers to access, linkage, and use of local authority administrative data for population health research, practice, and policy in the United Kingdom. *BMC Public Health*, 22(1263), 1–13. <https://doi.org/10.1186/s12889-022-13187-9>
2. **Parkin, K.**, Crowley, R., Massou, E., Del Pozo Baños, M., Friedmann, Y., John, A., & Moore, A. (2023). *Towards Early Identification of Mental Health Problems in Children’s Social Care*. Retrieved from <https://whatworks-csc.org.uk/wp-content/uploads/towards-early-identification-of-mental-health-problems-in-childrens-social-care.pdf>
3. Crowley, R., **Parkin, K.**, Rocheteau, E., Massou, E., Friedmann, Y., John, A., Sippy, R., Liò, P., & Moore, A. (2025). Machine Learning for Prediction of Childhood Mental Health Problems in Social Care. *BJPsych Open*, 11(3), e86. <https://doi.org/10.1192/bjo.2025.32>
4. **Parkin, K.**, Crowley, R., Sippy, R., Hayat, S., Zhang, Y., Brewis, E., Marshall, N., Ramsay-Patel, T., Thirugnanasampanthan, V., Skinner, G., Fonagy, P., Brayne, C., & Moore, A. (2025). *Development of a Risk Factor Framework to inform Machine Learning Prediction of Young People’s Mental Health Problems: A Delphi Study* [Manuscript in preparation]. Department of Public Health and Primary Care, University of Cambridge.
5. Anokhina, A., Burdge, C., **Parkin, K.**, [other co-authors TBC], & Moore, A. (2025). *Public attitudes towards multi-agency data linkage for the early identification of children and young people at risk of mental health problems: A Citizens’ Jury approach* [Manuscript in preparation]. Department of Psychiatry, University of Cambridge.

Contents

Declaration.....	i
Abstract.....	ii
Acknowledgements.....	v
Funding and Disclaimers	vi
Manuscripts Arising from Work During this PhD	vii
Part of the Motivation behind this PhD.....	xvi
Abbreviations	xvii
1 Chapter 1: Introduction.....	1
1.1 Background	1
1.1.1 The problem: adverse childhood experiences (ACEs) and their impact.....	1
1.1.2 One possible solution (part 1): early identification of ACEs to support young people's mental health	3
1.1.3 One possible solution (part 2): linking routinely-collected data to identify ACEs and potentially predict mental health problems earlier.....	6
1.1.4 Justifications for earlier identification in spite of current service resourcing challenges	10
1.2 Summary of the rationale for this PhD project.....	11
1.3 Overview of the CADRE database and Timely project, and how this PhD fits within this package of work	12
2 Chapter 2: Thesis Aims, Research Questions, Structure and Scope	15
2.1 Overarching aims.....	15
2.1.1 Within the PhD	15
2.1.2 Beyond the PhD.....	15
2.2 Research questions.....	15
2.2.1 Overarching research questions	15
2.2.2 Specific research questions.....	15
2.3 Cross-cutting theme	16
2.4 Structure of the thesis	16
3 Chapter 3: Defining Adverse Childhood Experiences (ACEs)	19
3.1 Definition for PhD.....	19
3.2 Background to definition choice.....	21
4 Chapter 4: A Delphi Study of Risk Factors for Mental Health Problems	22
4.1 Declaration of contributions	23
4.2 Chapter overview	24
4.3 Introduction	24
4.3.1 Background to the problem and a gap for early identification tools	25
4.3.2 The present study	25
4.3.3 Addressing inbuilt biases and reducing health inequalities	27
4.3.4 Aims.....	27
4.4 Methods	28
4.4.1 Development of the prototype theoretical framework of risk factors.....	31

4.4.2	A note to the reader: ACEs versus all Delphi risk factors.....	31
4.4.3	Identifying experts in the field	32
4.4.4	Running the survey	32
4.4.5	Specific aims of each round	33
4.4.6	Methodology: acceptability of the overall approach, domain groupings, life course stages and use of individual risk factors (Rounds 1 and 2)	33
4.4.7	Methodology: ranking of domains (Rounds 2 and 3)	34
4.4.8	Methodology: life course stages of greatest salience (Rounds 2 and 3)	34
4.4.9	Methodology: ranking of risk factors (Round 3)	35
4.4.10	Data analysis and visualisation	35
4.4.11	Ethical approval	36
4.5	Results	36
4.5.1	Results – Part 1: broader results on the whole framework of risk factors and demographic data	36
4.5.2	Results – Part 2: ACEs only	48
4.6	Discussion	63
4.6.1	What was found	63
4.6.2	Strengths, limitations and challenges	66
4.7	Conclusions	69
4.8	Supplementary analysis	70
5	<i>Chapter 5: Measurement of ACEs in a Database of Routinely-Collected, Linked Data.....</i>	71
5.1	Declaration of contributions	72
5.2	Acknowledgements	73
5.3	Chapter overview	74
5.4	Introduction	74
5.4.1	Significance of the research	78
5.4.2	Aims	78
5.5	Methods	79
5.5.1	Selecting a database.....	79
5.5.2	Characterising the cohort and databases in the SAIL Databank and working with the data	81
5.5.3	Population	82
5.5.4	Data sources.....	83
5.5.5	Data management and pre-processing.....	84
5.5.6	Data access and information governance.....	85
5.5.7	A note to the reader: reporting small-value results	86
5.5.8	Data linkage.....	86
5.5.9	Characterising available databases.....	87
5.5.10	Code lists	91
5.5.11	Methods for measuring ACEs.....	91
5.6	Results	95
5.6.1	Basic demographic information	95
5.6.2	Measurability of ACEs	96
5.6.3	Main findings.....	97
5.7	Discussion	110
5.7.1	What was found	110
5.7.2	Strengths, limitations and challenges	117
5.8	Conclusions	122

6	<i>Chapter 6: Umbrella Review Update of Prevention and Early Interventions for Mental Health Problems following ACEs</i>	124
6.1	Declaration of contributions	125
6.2	Acknowledgements	125
6.3	Chapter overview	126
6.4	Introduction	126
6.4.1	Rationale	126
6.4.2	Important context to the review update	127
6.4.3	Background	127
6.4.4	Aims and research questions	129
6.4.5	Outcomes of interest	130
6.5	Methods	130
6.5.1	Protocol and registration	130
6.5.2	Eligibility criteria	131
6.5.3	Information sources and search strategy	131
6.5.4	Study selection and data management	132
6.5.5	Data collection/extraction process	133
6.5.6	Data items	133
6.5.7	Quality appraisal of individual studies	134
6.5.8	Synthesis of results	135
6.5.9	Ethical considerations	135
6.5.10	Deviations from the protocol	135
6.6	Results	137
6.6.1	Study selection	138
6.6.2	Results for primary research question	139
6.6.3	Results for secondary research questions	169
6.6.4	Intervention characteristics: Cohort identification	169
6.6.5	Intervention characteristics: Targeting or modifications for different cohorts	169
6.6.6	Intervention outcomes: Proposed mediators and moderators (for effectiveness, ineffectiveness and neutrality)	170
6.6.7	Intervention outcomes: Risks, unintended consequences or harms	174
6.6.8	Intervention outcomes: Cost-effectiveness	175
6.6.9	Intervention implementation: Barriers and enablers to successful implementation	178
6.7	Discussion	181
6.7.1	What was found	181
6.7.2	Strengths and limitations	186
6.7.3	Implications for practice	188
6.8	Conclusions	190
7	<i>Chapter 7: Discussion and Conclusions</i>	191
7.1	Chapter overview	191
7.2	Summary of findings	191
7.2.1	Prediction of young people's mental health problems:	191
7.2.2	Measurement of ACEs:	193
7.2.3	Intervening following exposure to ACEs:	200
7.2.4	Overarching research questions:	203
7.2.5	Cross-cutting theme:	204
7.3	Strengths and limitations of the thesis	206
7.3.1	Definition of ACEs:	206
7.3.2	Who was present and who was absent	208

7.3.3	Re-use of existing data for research purposes.....	210
7.3.4	Scope, scale, novelty, cohesion, and contribution to the wider field.....	212
7.4	Future work	214
7.5	Conclusions	216
8	<i>Bibliography.....</i>	218
9	<i>Appendices.....</i>	250
9.1	Appendix A – Chapter 4: A Delphi Study of Risk Factors for Mental Health Problems	250
9.1.1	Appendix A.1 – Ranked risk factors within domains 1-8	250
9.1.2	Appendix A.2 – Unranked risk factors.....	266
9.1.3	Appendix A.3 – Heat maps for domains 1-8	267
9.1.4	Appendix A.4 – Final theoretical framework of risk factors	275
9.1.5	Appendix A.5 – Additional information available upon request	285
9.1.6	Appendix A.6 – Supplementary analysis: mapping Delphi risk factors for mental health problems to SAIL data dictionaries	286
9.2	Appendix B – Chapter 5: Measurement of ACEs in a Database of Routinely-Collected, Linked Data	301
9.2.1	Appendix B.1 – Different databases within SAIL.....	301
9.2.2	Appendix B.2 – Writing code lists to measure ACEs in SAIL	314
9.2.3	Appendix B.3 – Development of the ADP’s code lists for confirmed and possible maltreatment	322
9.2.4	Appendix B.4 – Step-by-step methods for measuring ACEs	324
9.2.5	Appendix B.5 – Additional technical detail about ALF assignment and data linkage in the SAIL Databank	332
9.3	Appendix C – Chapter 6: Umbrella Review Update of Prevention and Early Interventions for Mental Health Problems following ACEs	333
9.3.1	Appendix C.1 – Additional methodological details.....	333
9.3.2	Appendix C.2 – Search strategy	340
9.3.3	Appendix C.3 – Modified and annotated AMSTAR 2 tool.....	343
9.3.4	Appendix C.4 – Additional results tables	347
9.3.5	Appendix C.5 – References for 82 included papers	358

List of Tables

Table 1: Number of respondents who completed at least one question per round (i.e. classed as survey respondents)	37
Table 2: Demographics of individuals from Rounds 1 and 2 (i.e. pre- and post-purposive sampling) who completed at least one part of the survey	38
Table 3: Consensus results for each area consulted on in Round 1	41
Table 4: Feedback acted upon from Round 1	42
Table 5: Feedback not acted upon from Round 1 and rationale for decision	42
Table 6: Selected quotes from Round 2 respondents about alterations to framework from Round 1	43
Table 7: Feedback acted upon from Round 2	43
Table 8: Feedback not acted upon from Round 2 and rationale for decision	44
Table 9: Averages and range of rankings for each domain, listed in the approximate order in which they were ranked in Round 2	44
Table 10: Final ranked position of each domain after Round 3 in terms of importance for mental health prediction	44
Table 11: Descriptive results for questions requiring consensus to be reached	45
Table 12: Number of raters per domain	45
Table 13: Number of respondents per domain providing their self-rated level of expertise	46
Table 14: Summary of the main changes to the framework over all three rounds	48
Table 15: Proportion of importance by life course stage for ACEs from domains 1-7	52
Table 16: Proportion of importance by life course stage for ACEs from domain 8 (i.e. relating to under-served populations)	55
Table 17: Ranked importance of ACEs within domains; results for domains 1-7	58
Table 18: Ranked importance of ACEs within domain; results for domain 8 (i.e. relating to under-served populations)	61
Table 19: Abridged version of comparison between various databases and the CADRE database	80
Table 20: Database groupings for presentation purposes	87
Table 21: Temporal coverage of the 18 databases	89
Table 22: Number and percentage of individuals from Timely team cohort present in each database	90
Table 23: Table of measurable versus unmeasurable ACEs within the SAIL databases, and details of which data sources could be used to measure each ACE	92
Table 24: Number and percentage of young people in my cohort (broken down by sex) in each database	96
Table 25: Number of young people exposed to each ACE type, regardless of database	98
Table 26: Number of young people exposed to each ACE type, broken down by sex	100
Table 27: Number of young people who experienced at least one ACE in each database	104
Table 28: Number and proportion (%) of young people per database exposed to each type of ACE	107
Table 29: Most commonly recorded ACE per database	108
Table 30: Comparison of the prevalence of ACEs in the present study versus two other studies using survey methods	114
Table 31: Study inclusion criteria	131
Table 32: Items for data extraction	134
Table 33: Key and notation explanation for results relating to the primary research question	139
Table 34: Quality appraisal of studies (Abuse and Neglect)	142
Table 35: Study characteristics and summary of findings (Abuse and Neglect)	143
Table 36: Quality appraisal of studies (Unstable Housing)	147
Table 37: Study characteristics and summary of findings (Unstable Housing)	148
Table 38: Quality appraisal of studies (Household Adversity)	152
Table 39: Study characteristics and summary of findings (Household Adversity)	154

Table 40: Quality appraisal of studies (Involvement with Child Protective Services (CPS) or Living in Care).....	162
Table 41: Study characteristics and summary of findings (Involvement with Child Protective Services CPS) or Living in Care).....	164
Table 42: Examples of proposed mediators and moderators, grouped by factor type	172
Table 43: Proposed potential cost-effectiveness	177
Table 44: Summary of the measurability and intervenability of different ACEs, according to the findings of this thesis	204
Table 45: Ranked importance of risk factors within domain 1: Social and Environmental	250
Table 46: Ranked importance of risk factors within domain 2: Behavioural	254
Table 47: Ranked importance of risk factors within domain 3: Education and Employment.....	255
Table 48: Ranked importance of risk factors within domain 4: Biomarkers	256
Table 49: Ranked importance of risk factors within domain 5: Physical Health	258
Table 50: Ranked importance of risk factors within domain 6: Psychological and Mental Health....	260
Table 51: Ranked importance of risk factors within domain 7: Patterns of Service Use	261
Table 52: Ranked importance of risk factors within domain 8: Factors Identified to be Particularly Relevant to Under-Served Populations	262
Table 53: Risk factors which no respondent was able to rate; results for domains 1-8	266
Table 54: How the measurement of risk factors was defined.....	287
Table 55: Qualitative table to show which risk factors we considered to be measurable in each database.....	289
Table 56: Qualitative table to show which risk factors specifically relating to under-served populations we considered to be measurable in each database	297
Table 57: Descriptions of databases	301
Table 58: ACEs mapped to Delphi risk factors and proposed SAIL variables	314
Table 59: Study inclusion and exclusion criteria.....	333
Table 60: Points of clarification regarding methodology	339
Table 61: Amended search strategy for Embase	340
Table 62: Information about ACE exposure (Abuse and Neglect).....	347
Table 63: Information about ACE exposure (Unstable Housing).....	348
Table 64: Information about ACE exposure (Household Adversity)	349
Table 65: Information about ACE exposure (Involvement with Child Protective Services (CPS) or Living in Care).....	351
Table 66: Examples of cohort identification methods.....	353
Table 67: Further detail on examples of modifications/tailoring, grouped by theme.....	355

List of Figures

Figure 1: Literature map showing most highly connected papers to Felitti and colleagues' (1998) ACES paper.....	2
Figure 2: Dahlgren and Whitehead's updated model of the main determinants of health (2021)	8
Figure 3: Diagram to illustrate CADRE database sources [left side] and uses [right side]	13
Figure 4: Simplified project structure showing the overarching research questions and each study.	17
Figure 5: Diagram to show the project scope in the wider context of ACE prevention.....	18
Figure 6: Infographic of ACEs definition	20
Figure 7: Diagram to illustrate stages of the study	30
Figure 8: Top five ranked risk factors in each domain.....	47
Figure 9: Heat map to illustrate where in the life course exposure to ACEs is particularly harmful for the mental health outcomes of young people (domains 1-7).....	51
Figure 10: Heat map to illustrate where in the life course exposure to ACEs is particularly harmful for the mental health outcomes of young people from under-served populations (domain 8).....	54
Figure 11: Position of ACEs among top five ranked risk factors within domains	57
Figure 12: Representation of the gap between measurable ACEs and the unknown true prevalence of ACEs, along with factors affecting this gap	78
Figure 13: Framework for carrying out analysis and presenting results	82
Figure 14: Flowchart of access process for SAIL.....	85
Figure 15: Temporal coverage of the 18 databases	88
Figure 16: Prevalence of different ACEs experienced by young people in the linked database, in descending order	99
Figure 17: Girls versus boys exposed to each ACE type, presented as proportions of exposure	101
Figure 18: Girls versus boys exposed to each ACE type, presented as total number of people exposed	102
Figure 19: Proportion of ACEs per single-agency database (in descending order), with the total proportion in the linked database (last bar).....	105
Figure 20: Diagram to represent my approximate degree of confidence in the measurement of each ACE type, with details of some reasons underlying the degree of confidence.....	121
Figure 21: Decision flowchart for screening	136
Figure 22: PRISMA flowchart	138
Figure 23: Diagram to represent my approximate confidence in the measurement of each ACE type, with details of some reasons underlying the degree of confidence	195
Figure 24: Heat map to illustrate where in the life course exposure to risk factors is most harmful for young people's mental health outcomes (Domain 1: Social and Environmental; society- and family/caregiver-level factors).....	267
Figure 25: Heat map to illustrate where in the life course exposure to risk factors is most harmful for young people's mental health outcomes (Domain 2: Behavioural).....	269
Figure 26: Heat map to illustrate where in the life course exposure to risk factors is most harmful for young people's mental health outcomes (Domain 3: Education and Employment)	269
Figure 27: Heat map to illustrate where in the life course exposure to risk factors is most harmful for young people's mental health outcomes (Domain 4: Biomarkers).....	270
Figure 28: Heat map to illustrate where in the life course exposure to risk factors is most harmful for young people's mental health outcomes (Domain 5: Physical Health)	271
Figure 29: Heat map to illustrate where in the life course exposure to risk factors is most harmful for young people's mental health outcomes (Domain 6: Psychological and Mental Health)	272
Figure 30: Heat map to illustrate where in the life course exposure to risk factors is most harmful for young people's mental health outcomes (Domain 7: Patterns of Service Use).....	272

Figure 31: Heat map to illustrate where in the life course exposure to risk factors is most harmful for young people’s mental health outcomes (Domain 8: Factors Identified to be Particularly Relevant to Under-Served Populations; society- and family/caregiver-level factors).	273
Figure 32: Final theoretical framework based on the Delphi consensus-building process.....	275

Part of the Motivation behind this PhD

As a teenager, I read a novel called 'Boy A' by Jonathan Trigell. Through an almost case study-like style, the novel described a young boy's life, pitted with events which led to a gradual spiral into committing an awful crime. What struck me about this book was the incredible and devastating snowball effect of seemingly small occurrences, and also how there were so many opportunities for an adult to intervene, through a seemingly small act that would have totally changed Boy A's trajectory. Though this book's outcome was a criminal act, Boy A's trajectory could so easily have been to poor mental health instead, and it could also have been to more hopeful conclusions. Although this was fictional, it could have been the story of any number of young people, many of whom we hear about in the news and many of whom go unheard and unseen.

Around the same time, I also volunteered as a sports leader at school sports clubs and special educational needs clubs. And there I was able to see again what seemingly small things like a holiday club or activities with peers could do for children.

My mum also worked as an Inclusion Officer in a school in an area with high levels of deprivation, and then subsequently ran a youth project, including a youth club in a similar area. We'd talk about the impact of the systems young people were part of, and their interactions with these systems, including their immediate family, extended family, school, community projects, social services, and the police.

Then, as an adult, pursuing a career in child psychology, and working as an assistant psychologist in a community mental health service for adults, I was struck by how many of the adults I worked with, regardless of diagnosis, had early life adversity or trauma. Childhood trauma and adversity became more of a topic of interest for me and something I researched in my spare time, in collaboration with my NHS supervisor (Dr Youngsuk Kim) and previous university supervisor (Dr Jason Rentfrow). This project in my spare time then morphed into a PhD application, and eventually a PhD place, the outcome of which is presented in this thesis.

Many other things, small and big, led me towards this PhD and these topics, but these are just a few that stand out and give some context of why these topics, why these methods and why this matters to me.

Abbreviations

A&E	Accident and Emergency services
ACE(s)	Adverse childhood experience(s)
ADP	Adolescent Mental Health Data Platform
AI	Artificial Intelligence
ALF	Anonymous Linking Field (i.e. an ID allocated to individual records in the SAIL Databank)
CADRE	Child and Adolescent Data REsource (formerly known as Cam-CHILD)
Cam-CHILD	Cambridge Child Health Informatics and Linked Data (now known as CADRE)
CAMHS	Child and Adolescent Mental Health Services
CPS	Child protective services
EHR	Electronic health record
GP	General Practitioner (a health professional in primary care) and General Practice (i.e. work setting of a General Practitioner)
IGRP	Information Governance Review Panel (i.e. the application review panel for the SAIL Databank)
IPV	Interpersonal violence
IQR	Interquartile range
LA	Local Authority
MH	Mental health
ML	Machine Learning
NHS	National Health Service (i.e. public healthcare service in the UK)
NLP	Natural Language Processing
ONS	Office for National Statistics
SAIL Databank	Secure Anonymised Information Linkage Databank
SD	Standard deviation
SQL	Structured Query Language
TRE	Trusted Research Environment
WHO	World Health Organization

1 Chapter 1: Introduction

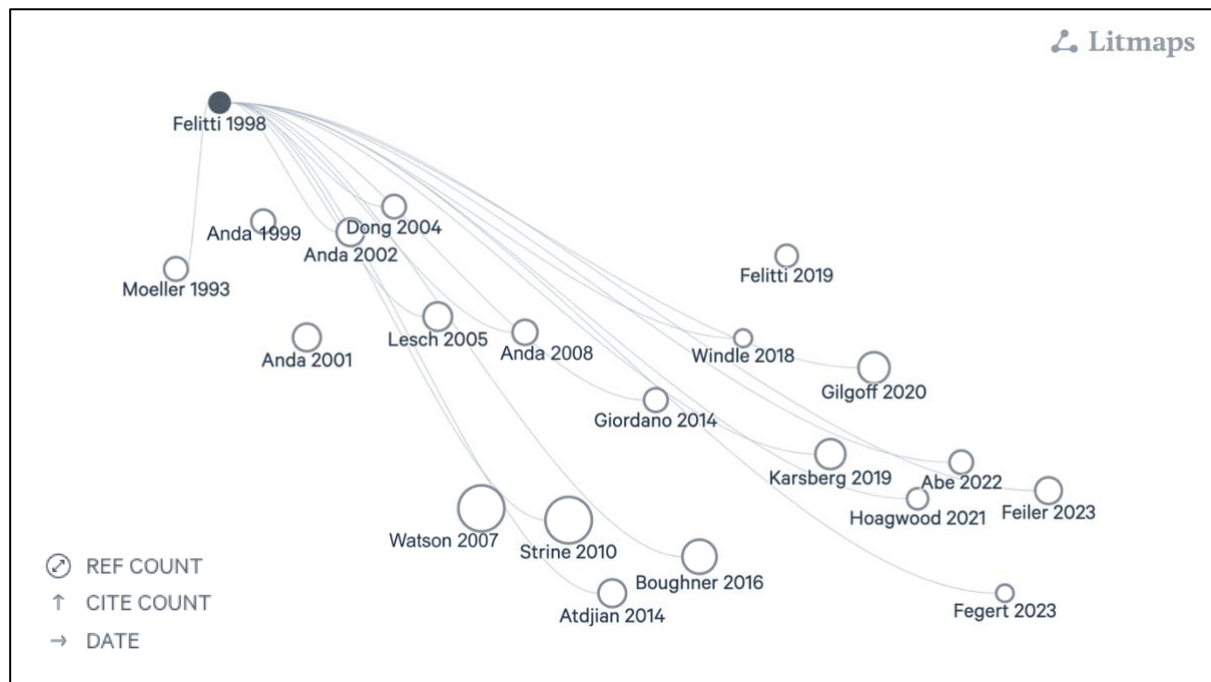
1.1 Background

1.1.1 The problem: adverse childhood experiences (ACEs) and their impact

Over the last three decades, there has been increasing interest in the role that early life adversity may play in lifelong outcomes. Evidence has come from cross-sectional and longitudinal studies, or studies in which people are studied for both their mental health and also asked about early life experiences, with comparisons made between groups. Such studies have provided evidence for specific ‘risk’ and ‘protective’ factors, with some risk factors being grouped together and termed ‘adverse childhood experiences’ or ‘ACEs’. The umbrella term ‘ACEs’ covers a highly varied group of experiences including classic traumas and non-traumas, which have been grouped together due to the evidence of their association with negative outcomes in later life. They can be conceptualised as experiences occurring along a continuum ranging from impersonal trauma, to interpersonal trauma, to attachment trauma or complex trauma (Bateman, Fonagy, Campbell, Luyten, & Debbané, 2023). Impersonal traumas involve a ‘non-human agent’ and include experiences such as living through natural disasters. In contrast, interpersonal traumas involve a ‘human agent’, for example being bullied or physically abused by a classmate. Finally, attachment trauma or complex trauma involves an attachment figure and would include experiences like abuse or neglect by a parent or guardian. Other ACEs (for example, parental separation or divorce) do not necessarily fit into any of these trauma categorisations and instead are only distressing or adverse to some young people, and may be neutral or even beneficial to others.

In 1998, a seminal paper – ‘the Adverse Childhood Experiences Study’ – was published, popularising the term ‘adverse childhood experiences’ (or ‘ACEs’) and drawing attention to this issue (ACE Study; Felitti et al., 1998). According to Google Scholar, this paper has been cited over 23,200 times (as of 9th August 2024), and numerous papers have been published which relate to this paper, with just a few of the most highly connected papers shown in the literature map in Figure 1.

Figure 1: Literature map showing most highly connected papers to Felitti and colleagues' (1998) ACES paper
(produced using: <https://www.litmaps.com/>)



In the Adverse Childhood Experiences Study, just over half of respondents (52.1%) reported having experienced at least one form of ACE, whilst a little over one in 20 (6.2%) reported having experienced four or more ACEs (Felitti et al., 1998). Later studies suggested that this number may even be higher, with Merrick and colleagues (2018) reporting that the prevalence is around 62% for single ACEs and 25% for three or more ACEs. In addition to being relatively common, there is convincing evidence that ACEs can have a detrimental impact across the life course. For example, exposure to ACEs has been associated with harm to health, wellbeing and opportunity, such as educational attainment and employment (Center for Disease Control and Prevention, 2019; Nelson et al., 2020). Furthermore, ACEs are associated with mental health problems in childhood (Center for Disease Control and Prevention, 2019; Corwin et al., 2015; Sahle, Reavley, Li, et al., 2021; Sederer, 2016) and adulthood (Sahle, Reavley, Li, et al., 2021; Satinsky et al., 2021). In fact, according to the former president of the American Academy of Pediatrics, Dr. Robert Block, “Adverse childhood experiences are the single greatest unaddressed public health threat facing our nation today” (TED, 2014), a claim which still seems as true now, a decade later.

Exposure to ACEs tends not to be equally distributed and those who have experienced one ACE are at a higher risk of experiencing others. Felitti and colleagues (1998) found that for people who reported any single category of ACE, the probability of exposure to any subsequent categories was as much as 65-93%. Moreover, the ACE Study (1998) highlighted a dose-response relationship between the

number of categories of ACEs and the number and severity of risk factors for illness, psychosocial problems and behavioural problems (for example, depression, suicide attempts, alcoholism and physical inactivity). In addition, there was also a dose-response relationship between the number and severity of ACEs a person was exposed to and their risk of serious disease and physical health problems. Going beyond ACE counts alone, Lacey and colleagues used latent class analysis to understand how certain ACEs cluster together, and also how this interplays with experiences of poverty (Lacey, Howe, Kelly-Irving, Bartley, & Kelly, 2020). Their findings showed that some types of ACE are more likely to co-occur with other types of ACE, though they noted that neither the death of a close family member nor sexual abuse clustered with other adversities.

As well as the personal cost to individuals, the societal burden of ACEs is enormous, with a study in the Netherlands highlighting an association between ACEs and 20.7 YLD/1000 (years lost due to disability in the population). This is compared to 12.9 YLD/1000 for all mental disorders combined (Cuijpers et al., 2011), highlighting the burden ACEs can have at a population health level. In a recent study by Bellis et al. (2019), the total annual costs attributable to ACEs were estimated at \$581 billion in Europe and \$748 billion in North America. Moreover, more than 75% of these costs were linked to individuals with two or more ACEs. This high personal and economic burden is pitted against a landscape where statutory services are required to do more and more with limited resources (British Medical Association, 2024). Secondary prevention and early intervention approaches potentially offer a promising solution as they are often more effective and less expensive overall than offering treatment after difficulties arise (G. Allen, 2011). Societies should also seek to address the causes of exposure to ACEs in the first place, and undoubtedly, there will always be a need for treatment. However, secondary prevention and early intervention could shift the population curve so that fewer people experience the greatest difficulties (Rose, 2001).

1.1.2 One possible solution (part 1): early identification of ACEs to support young people's mental health

Despite good evidence that exposure to ACEs increases an individual's risk for a variety of mental health problems, ACEs are not currently used to predict a young person's risk of mental health problems later in life (i.e. as a method of early identification). At present, very few prediction tools are available for clinical use within psychiatry or mental health. A rare example of a prediction tool in clinical use is the Management and Supervision Tool (MaST), a decision support platform which uses artificial intelligence (AI) to predict people's risk of requiring crisis care, thus helping mental health staff plan resources and provide safer and higher quality care (Gadd, 2020; Holmusk, 2024). MaST has

been deployed in Mersey Care NHS Foundation Trust and, as of 2020, was looking to be implemented in other Trusts. Though clinical implementation like this is rare, some other prediction tools have shown demonstrations of principle or exist in research settings (Chekroud et al., 2016; Hossain, Khan, Moni, & Uddin, 2019).

Given this context, early identification currently relies on young people or their caregivers presenting to services such as General Practices (GPs) or being identified as having difficulties by their teachers or others without specialist mental health training; it is only after this that young people may be screened by a professional with mental health expertise (stem4, 2019). As described by the Goldberg-Huxley model, people have to pass through a series of obstacles (or so-called ‘filters’) between different levels of care, before reaching specialist psychiatric care (Huxley, 1996). Moreover, the model posits that each filter is selectively permeable meaning that some individuals have access to different levels of care more easily than others. This series of steps to access specialist psychiatric care can lead to delays in diagnosis, as well as meaning that young people have to be in enough distress (or causing sufficient concern to others) to warrant visiting healthcare services, which often means they have lived with difficulties for some time. Furthermore, some groups of people will be disinclined to seek support from healthcare providers or have reduced access to such services (Kreps, 2017; McFadden et al., 2018; Whitley, Kirmayer, & Groleau, 2006), which can introduce or exacerbate health inequalities (Marmot, 2010). Many young people who need support for their mental health never have contact with mental health services. The Children’s Commissioner noted that in England, in the financial year 2021/22, of the 1.4 million children estimated to have a mental health problem, less than half received at least one contact with children and young people’s mental health services and just 34% received at least two contacts (Children’s Commissioner, 2023).

Once emerging mental health problems have been identified, young people and their families face further issues. Services which are commissioned to support young people with mental health problems experience demand for services which far outstrips capacity (NHS Providers, 2019), leading to long waiting lists for treatment and increased referral thresholds, requiring young people to be more unwell before they can access mental health support (Care Quality Commission, 2018; Children’s Commissioner, 2023). As such, children may present with difficulties and be referred to CAMHS (i.e. Child and Adolescent Mental Health Services), but be declined from services due to not meeting these high thresholds. Due to service fragmentation, children who are not yet unwell enough for CAMHS end up ‘falling between the cracks’, and those who are accepted to CAMHS are much more unwell before they receive treatment. This is distressing for young people, their families, and professionals

too. For those who are assessed and accepted into CAMHS, they face further delays in receiving treatment (Children's Commissioner, 2023). It is worth considering too that this waiting period is a large proportion of a young person's relatively short life and may coincide with major milestones, such as moving to secondary school and completing exams, so delays in appropriate support can have far-reaching consequences even into adulthood (e.g. poor attainment leading to poor employment prospects). Reduced prospects can then increase the risk of subsequent mental health problems (Compton & Shim, 2015; Marmot, Friel, Bell, Houweling, & Taylor, 2008; What Works Wellbeing, 2017). Although by no means irreversible, this can be harder to mitigate later. Those who experience early adversity also face a snowball effect with adversity begetting further adversity (Di Lemma et al., 2019; Dong et al., 2004; K. Hughes et al., 2017).

What is needed are interventions and services for those young people who are not unwell enough for CAMHS, but still require mental health support. Moreover, there needs to be a method to identify these young people early so that they can receive timely and proportionate support.

1.1.2.1 In support of earlier identification and early interventions

Countless organisations and advocates, as well as much of the public, support earlier intervention for mental health problems (see for example, Children's Commissioner, 2023; Davey & McGorry, 2019; Filkin et al., 2023; Mental Health Taskforce, 2016). Furthermore, many call for more proactive efforts with respect to ACEs, either by intervening to prevent their occurrence (Geeraert, Van den Noortgate, Grietens, & Onghena, 2004; Guterman, Banman, & Bellamy, 2018), or by identifying children after exposure so that poor outcomes can be prevented or mitigated (Liming & Grube, 2018).

In addition to the human benefit of early intervention, there are also compelling economic arguments for it, with evidence to suggest that support early in life might avoid higher costs later on (see for example, Arias, Saxena, & Verguet, 2022; GBD 2019 Mental Health Disorders Collaborators, 2022; Heckman, 2012; McDaid & Park, 2022; The Academy of Medical Sciences, 2024). Moreover, there are economic arguments for early intervention following exposure to ACEs specifically (Bellis et al., 2023).

Earlier interventions depend on earlier identification, so a mechanism is needed to facilitate this identification. ACEs do not sufficiently meet the criteria set out by the UK National Screening Committee (2015) to warrant a national screening programme or routine enquiry (Gentry & Paterson, 2021). However, they may be able to be used to support earlier identification of at-risk young people, and targeting of early interventions to promote mental health and wellbeing.

1.1.3 One possible solution (part 2): linking routinely-collected data to identify ACEs and potentially predict mental health problems earlier

One possible way to identify ACEs, and potentially identify emerging mental health problems earlier, is through secondary analysis of existing data. In particular, analysis of the vast amounts of data that are routinely-collected during young people's interactions with everyday services, such as schools, and community healthcare services (e.g. GP), as well as acute services, such as acute healthcare services (e.g. A&E) or social services. 'Routinely-collected data' are also known as 'routine data' and 'administrative data', and the three terms are used interchangeably throughout this thesis.

Throughout a young person's lifetime, they interact with a host of statutory services. As such, a wealth of data are collected about them and stored across different record systems, including education, healthcare and social care. Data from one source alone may not be useful beyond the specific data collection setting, for example, poor school attainment is useful information to a school but less so for a GP. However, taken together, data on young people's interactions and 'contacts' with statutory services could provide valuable insights into young people's life experiences (including exposure to ACEs) and how they are faring, and have potential predictive utility for identifying emerging problems, such as mental health problems. Currently, these databases largely go unused beyond their primary purpose and their potential remains untapped. If linked together and considered longitudinally, these databases may offer valuable insights into what confers risk and resilience for mental health problems, as well as early indications of arising issues and opportunities for intervention (Wykes et al., 2021).

In 'The Five Year Forward View for Mental Health', the Mental Health Taskforce (2016) stated:

"The Taskforce heard from a range of stakeholder organisations that data and transparency are critical aspects of a system that delivers good outcomes. Work needs to happen to link data from different public services and agencies (the NHS, social care, education, criminal justice and others) to help identify and meet the full needs of people with mental health problems. Similarly, there should be more national support with the analysis and presentation of raw data to support good commissioning and local planning." (Mental Health Taskforce, 2016)

Moreover, as an organisation seeking to increase data linkage of routine data, the Administrative Data Research UK's (ADR UK) mission statement says:

“By joining up the abundance of administrative data already being created by government and public bodies across the UK....we are enabling vital research that has the potential to lead to better informed policy decisions and more effective public services.” (ADR UK, 2021)

If ACEs are in some ways predictive of mental health problems, as indicated by the literature previously referenced, then identifying ACEs might provide one route to break this chain. If young people who have experienced ACEs can be detected, then it may be possible to offer earlier and proportionate interventions where it is indicated. Crucially, exposure to ACEs does not always lead to poor mental health outcomes; many young people experience ACEs with no notable poor outcome, and some people even report some positive outcomes such as ‘post-traumatic growth’ (see for example, Chamberlain et al., 2019; Seery, 2011; Simsek Arslan, Özer, & Buldukoglu, 2022; Weetman, Kiemle, Lowe, & Balfour, 2022). However, this could just be one way to detect an over-inclusive pool of young people who may be worth considering for additional support. Identifying young people in this way could facilitate the running of rigorous trials to see if such a pre-emptive approach (i.e. a form of screening) might be beneficial, as well as help to identify possible harms and unintended consequences.

A further issue which could be helped by data linkage is that of oversight and coordination. Specifically, one way to facilitate better oversight of young people’s experiences, as well as support service coordination, is having a shared database of information relating to a young person, with data linked from various agencies, and tools to flag if multiple signals from different sources indicate that professionals should take a closer look. For example, if a teacher has concerns about a child’s attendance at school and the General Practitioner (GP) has separate concerns about poor physical development or inability to thrive, combined with multiple attendances at Accident and Emergency (A&E). Using data linkage, this information could all be considered together, and better informed actions could be taken.

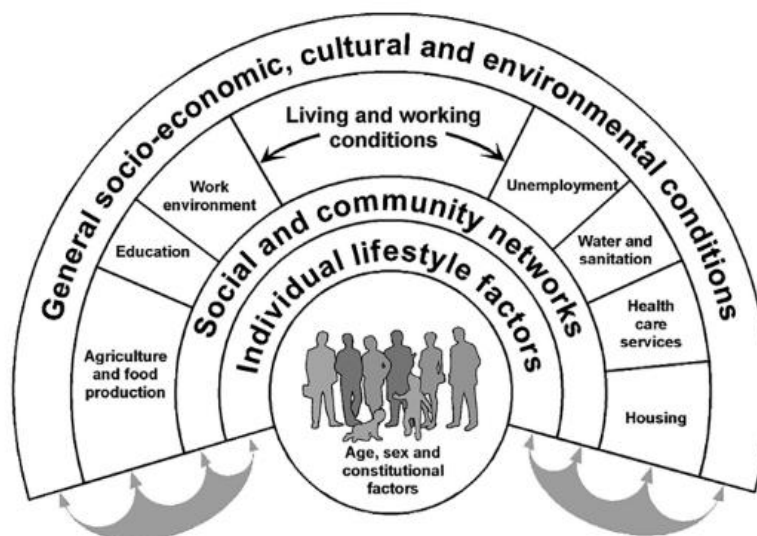
1.1.3.1 Professional support for a holistic and joined up approach, with the inclusion of information on ACEs, to protect young people and support their wellbeing

It has long been understood that health is determined by a huge variety of factors and the term ‘the social determinants of health’ has become popularised in recognition of the many contributors to health. Social determinants are the “causes of the causes” of ill health (Marmot, 2005; Rose, 1992; Sederer, 2016). According to the World Health Organization (WHO), the social determinants of mental

health are the conditions in which we “are born, grow, live, work and age, and the wider set of forces and systems shaping the conditions of daily life” (World Health Organization, 2024).

Often health is incorrectly conflated with health care, yet 90% of the determinants of our health stem from our lifetime social and physical environment (Sederer, 2016). This idea was illustrated by Dahlgren and Whitehead in their model of the main determinants of health, otherwise known as ‘The Rainbow Model’ (Dahlgren & Whitehead, 1991); this frequently used model was tweaked 30 years later and is shown in Figure 2 (Dahlgren & Whitehead, 2021).

Figure 2: Dahlgren and Whitehead’s updated model of the main determinants of health (2021)



Source: adapted from Dahlgren and Whitehead, 1991

In practice, the idea of the many determinants of health is well-illustrated by the following quote from the Children’s Commissioner report in 2023:

“When I think about children’s mental health it is clear to me that we need to think holistically about a child. So much of a child’s wellbeing will be down to things such as their relationships with family and friends, their participation in education, or their experiences of the online world. That is why a preventative approach is essential...” (Children’s Commissioner, 2023)

Many professionals are keen for these different health determinants to be built into our approach to young people’s wellbeing and care. For example, in the recently published ‘A Covenant for Health’, Lord Filkin CBE and colleagues (2023) called for:

“Health in all Policies: the wider social, environmental, economic and commercial determinants of poor health need to be persistently addressed. So, adopt health in all policies

at both central and local level to assess the health impact of policies, and publish them transparently.” (Filkin et al., 2023)

In addition, professionals who care about young people’s welfare have long been calling for better coordination and liaison between organisations, as well as the consideration of ACEs, to protect the wellbeing of young people (All Party Parliamentary Group on a Fit and Healthy Childhood, 2024; Bellis et al., 2023; Doughty, 2024; Mental Health Taskforce, 2016).

Moreover, in extreme cases, such as serious case reviews, lack of inter-agency coordination, oversight and awareness have consistently been cited as major issues preceding the significant harm or death of a child (BBC, 2005; Sellgren, 2010). Serious case reviews and inquiries often highlight warning signs that were missed by statutory services, for example, flags like significant amounts of service contact in the cases of Victoria Climbié (Laming, 2003) and Peter Connelly (aka ‘Baby P’) (A. Jones, 2009), or conversely, the unusually low amount of contact and absence from routine appointments such as immunisations in the case of Hamzah Khan (Maddocks, 2013). Information sharing, or lack thereof, is persistently raised as a problem preceding these tragedies.

The National Review into the murders of Arthur Labinjo-Hughes and Star Hobson (May 2022) stated:

“Problems with information sharing have been raised by every national child protection review and inquiry - going back as far as the inquiry into the death of Maria Colwell in 1973... Time and again we see that different agencies hold pieces of the same puzzle but no one holds all of the pieces or is seeking to put them together...”

Effective data systems is [sic] something we already expect for professionals operating in other high risk contexts, for example, counter terrorism and aviation. We must now expect the same for professionals working to protect some of the most vulnerable in society.”

(The Child Safeguarding Practice Review Panel, 2022)

This reference to holding “pieces of the same puzzle” across the system was the reason for this thesis’s title; I found this notion compelling for a number of reasons when considering ACEs. Firstly, it directly relates to the idea of measuring ACEs across different data sources using linked data, as I seek to do in Chapter 5. However, the idea of puzzle pieces also neatly reflects the idea of the Delphi study in Chapter 4, acknowledging that ACEs are part of a wider picture of young people’s mental health, not the whole picture. Stretching the metaphor further, secondary prevention and early intervention (as

described in Chapter 6) are part of the care pathway puzzle that is often overlooked in favour of treatment after mental health problems have already developed, or in many cases missing altogether, for the many young people who need support but do not receive it.

1.1.4 Justifications for earlier identification in spite of current service resourcing challenges

If mental health services and many other services working with young people are already over-stretched, one might ask how it can be justified to identify more people who might benefit from additional support and how this support can be provided. A key factor here is what are the short and longer term benefits from such early intervention, which requires a clear evidence base. Some reasons why earlier identification may be an area worth pursuing in spite of resourcing challenges are listed below:

- There is appetite for earlier intervention for mental health from the people this concerns. For example, during Citizens' Juries and Patient and Public Involvement Groups (PPI) groups convened by our team (the Timely team), adults said that their lives could have been greatly changed if care pathways looked different and made better use of data for early identification (DARE UK FAIR TREATMENT funding report: Moore et al., 2022).
- As described in earlier sections, there is compelling evidence for early intervention, and for increased consideration of ACEs. Along with support from people this concerns directly, countless professionals also advocate for this approach.
- There is poor investment in mental health, both clinically and in research. Firstly, in clinical practice, less than 1% of the total NHS budget is spent on children's mental health services (Rocks & Tsiachristas, 2019; YoungMinds, n.d.). In terms of research funding, the mental health charity MQ found that in 2014-2017, the total expenditure on mental health research averaged £124 million per year which translated as just £9 per person affected by mental illness; by comparison, £228 was spent on research into cancer per person affected (i.e. 25 times more) (MQ, 2017). Moreover, only 3.9% of research funding was put towards prevention of mental illness, and only 26% of money spent on mental health research was focused on young people. This is despite the fact that three quarters of mental illness is estimated to begin before the age of 18. It is arguable that less would be spent in later life and on treatment approaches if investment was more heavily front-loaded in early life. Identifying more young people in need of support is simply shedding light on an existing issue, rather than creating the issue. If demand exists, it exists regardless of whether it is measured or invested in.

- Related to the previous point, early identification and intervention is initially costly, but as illustrated in the economic arguments previously, there can be longer term pay off (see for example, McDaid & Park, 2022). Not least because young people go on to become adults (and often parents too), contributing to society in intellectual, emotional, creative and financial terms (see for example, The Academy of Medical Sciences, 2024). Early intervention for young people is an investment in them, but also in the future's adult population too.
- Using a similar principle to that of safeguarding, supporting young people's mental health and wellbeing can be seen as "everyone's business" – not just the responsibility of mental health services (Marmot, 2005, 2012; Marmot et al., 2008; World Health Organization, 2024). If child wellbeing is taken as a systems issue, there are system solutions which do not necessarily have to exacerbate demand on young people's mental health services. System solutions could involve things such as youth clubs, sports clubs, improved housing, community centres for families, employer support strategies for parents, and so on. This thesis seeks to explore the evidence base for certain types of early interventions following ACE exposure.
- Evidence suggests that ACE exposure in itself does not necessarily lead to poor outcomes; what is important is the context surrounding ACEs, including how adults respond, support networks around young people, and a person's cognitive appraisal of the ACE (Aafjes-van Doorn, Kamsteeg, & Silberschatz, 2020; Leung, Chan, & Ho, 2020; Wiseman, Hamilton-Giachritsis, & Hiller, 2021). It is incredibly challenging, though not impossible, to prevent ACEs from occurring (Center for Disease Control and Prevention, 2019). However, it may be possible to improve the context around young people following exposure to ACEs in order to increase the likelihood of positive outcomes. Secondary prevention can work in complement with primary and tertiary prevention.
- Though there is insufficient evidence of a need for national routine screening for ACEs (such as that implemented for breast and cervical screening in the UK) (Gentry & Paterson, 2021), being ACE-informed may be a potential way forward.

1.2 Summary of the rationale for this PhD project

ACEs are known to have a significant impact on mental health. Through this PhD project, I explored whether drawing on a range of information about ACEs experienced by individuals could improve the identification of young people at risk of mental health problems, and help their subsequent trajectories. Early identification and intervention is often assumed to be more effective than later treatment. To test such an approach, which effectively amounts to screening, first there has to be a reliable and feasible method of detecting ACEs; detection methods will need to align with the evidence

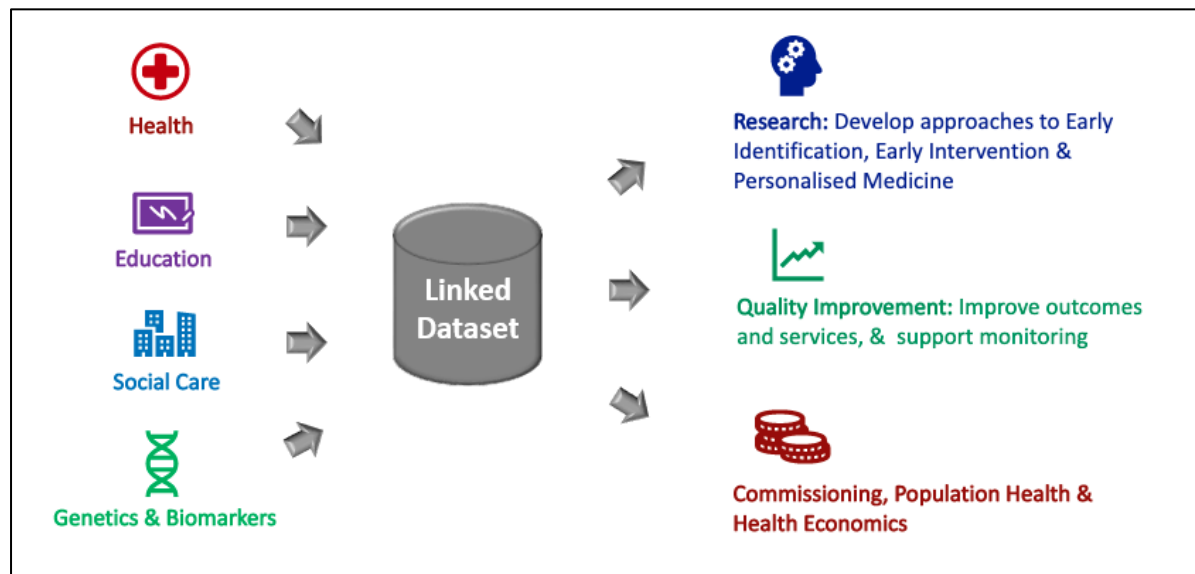
base for screening (e.g. being viable, effective and appropriate) (UK National Screening Committee, 2015).

There is currently no clear way to identify cohorts of at-risk young people early in order to offer early intervention. Understanding more about ACE exposure could lead to more personalised intervention where support and treatment is tailored to the individual. Furthermore, by charting the prevalence of different ACEs (as well as testing methodologies and writing code for carrying out this measurement), this project could support commissioners to make more effective use of limited resources for young people's mental health and wellbeing; this can be achieved by making commissioning decisions which match service funding to the local population needs.

1.3 Overview of the CADRE database and Timely project, and how this PhD fits within this package of work

My project ties into a wider programme of work, the 'Timely project', led by one of my supervisors, Dr Anna Moore. The Timely project is illustrated in Figure 3. It seeks to develop early identification tools to predict young people's mental health problems earlier, in order to facilitate more timely intervention. To develop these early identification tools, the team is building a de-identified, linked database of routinely-collected health (community, acute, and mental health), education, and social care data, combined with a research database of genetic data. This database will be known as 'CADRE' (the Child and Adolescent Data REsource), formerly known as 'Cam-CHILD' (Cambridge Child Health Informatics and Linked Data) before its geographical expansion necessitated a change of name.

Figure 3: Diagram to illustrate CADRE database sources [left side] and uses [right side]
(created by Dr Anna Moore)



CADRE includes records for most young people aged 0 to 17 years within a region, with the long-term aim of inclusion of data for people up to 25 years. CADRE is an extensible network of federated databases, initially being developed in the following regions: Cambridgeshire and Peterborough; Manchester; Birmingham; Liverpool; and Cardiff. Each regional database will exist in a near-real-time identifiable version which can be used by professionals, and a de-identified version which can be used by trusted researchers for approved projects pertaining to young people's health. The databases will form part of a network of other Trusted Research Environments (TREs), facilitating analysis of different populations of young people, with the aim of improving external validity/generalisability of findings.

CADRE is being used to build and test risk prediction models, leading to early identification tools (known as 'Timely' tools) for child and adolescent mental health problems. The Timely project is trialling different statistical approaches to risk prediction in order to understand which is the most accurate and interpretable for predicting young people's mental health problems earlier. These methods include traditional regression models, as well as various machine learning (ML) approaches.

The Timely team's work is premised on the notion that data linkage and machine learning approaches may offer a novel opportunity to capitalise on the vast amounts of data collected about young people throughout their childhood, including on ACEs, in order to facilitate early identification of emerging mental health problems. Mental health problems, such as depression, can follow a variety of trajectories, which can be obscured by relying on cross-sectional data; in contrast, analysis of longitudinal data may help to understand trajectories of mental health problems and could lead to a

better understanding and prediction of an individual's prognosis. This in turn could lead to a tailored approach to intervention, which is the aim of 'personalised medicine' (Baune, 2019).

It was initially planned that I would use the CADRE database for my PhD. However, its construction has taken longer than envisaged, in particular because of amending ethics agreements, and allowing time for developing relationships with service providers and putting data sharing agreements in place. As such, whilst the CADRE database was being built, I instead used a complementary database to develop methodologies, map risk factors for mental health problems, and develop code for extracting and analysing information on ACEs. This work will then be applied to the CADRE database to expedite analysis and also act as a crucial external validation step. At present, the learning from this complementary database continues to be used to inform the development of CADRE, for example, through learning how best to set up metadata and data conventions, learning about governance and training structures, exploring the missingness of variables (specifically mental health risk factors), and highlighting which databases tend to contain the most valuable information on risk factors for mental health problems.

2 Chapter 2: Thesis Aims, Research Questions, Structure and Scope

2.1 Overarching aims

2.1.1 Within the PhD

During the course of this PhD, the overarching aims were:

- To understand the extent to which it is possible to measure different adverse childhood experiences (ACEs) using routinely-collected data from healthcare, social care and education;
- To identify appropriate early interventions to help the mental health of young people who have experienced ACEs;
- To carry out each component of work with consideration for minimising health inequalities.

2.1.2 Beyond the PhD

In the longer term, this work aimed to contribute to the question of whether childhood mental health resource allocation decisions could be enhanced by taking an ACE-informed approach, i.e. by utilising evidence on the prevalence and impact of different ACEs.

2.2 Research questions

2.2.1 Overarching research questions

To what extent is it possible to measure different ACEs using routinely-collected data?

What can be done to mitigate any negative mental health impacts for young people who experience different ACEs?

2.2.2 Specific research questions

Prediction of young people's mental health problems:

- 1) How important are ACEs in the prediction or early identification of young people's mental health problems?
- 2) Where do ACEs fit in the context of other important risk factors for young people's mental health problems?

Measurement of ACEs:

- 3) According to routine data sources alone, what is the prevalence of ACE exposure in a geographically bound population of young people? How frequently are different ACEs recorded in routinely-collected data sources?
- 4) Which, if any, ACEs are not measurable using routinely-collected data?
- 5) Which routine data sources are the most and least helpful for the measurement of ACEs?
- 6) What, if any, value is added by linking multi-agency data compared to using single-agency data for the measurement of ACEs?

Intervening following exposure to ACEs:

- 7) What is the evidence base on intervention effectiveness for preventing or intervening early to support children and young people's mental health following exposure to ACEs?
- 8) What factors are important in order to implement these interventions successfully?

2.3 Cross-cutting theme

How can these questions be addressed in ways which minimise health inequalities?

2.4 Structure of the thesis

This thesis began with describing the context in which my project sat and the problems and gaps it sought to address. This is followed by the definitions used to conceptualise ACEs. The body of the thesis is made up of three chapters, each presenting a different study. Study one (Chapter 4) covers the development of a theoretical framework of mental health risk factors and subsequent Delphi study to refine this theoretical framework. Study two (Chapter 5) presents an investigation into the prevalence of different ACEs based on routinely-collected data from Wales, UK, and an exploration of the value of linked data compared to single-agency data when measuring ACEs. Study three (Chapter 6) describes an umbrella review (i.e. a systematic review of systematic reviews) of prevention and early interventions to mitigate mental health problems after experiencing ACEs. Figure 4 illustrates the aims of these three studies. Finally, the thesis ends with a discussion of what these three studies show about using information about ACEs, as well as routinely-collected linked data, to help the mental health of young people.

Figure 5 shows the scope of this thesis in relation to ACE prevention, with this project focusing purely on secondary prevention (i.e. mitigating negative impacts after ACEs have already occurred).

Figure 4: Simplified project structure showing the overarching research questions and each study

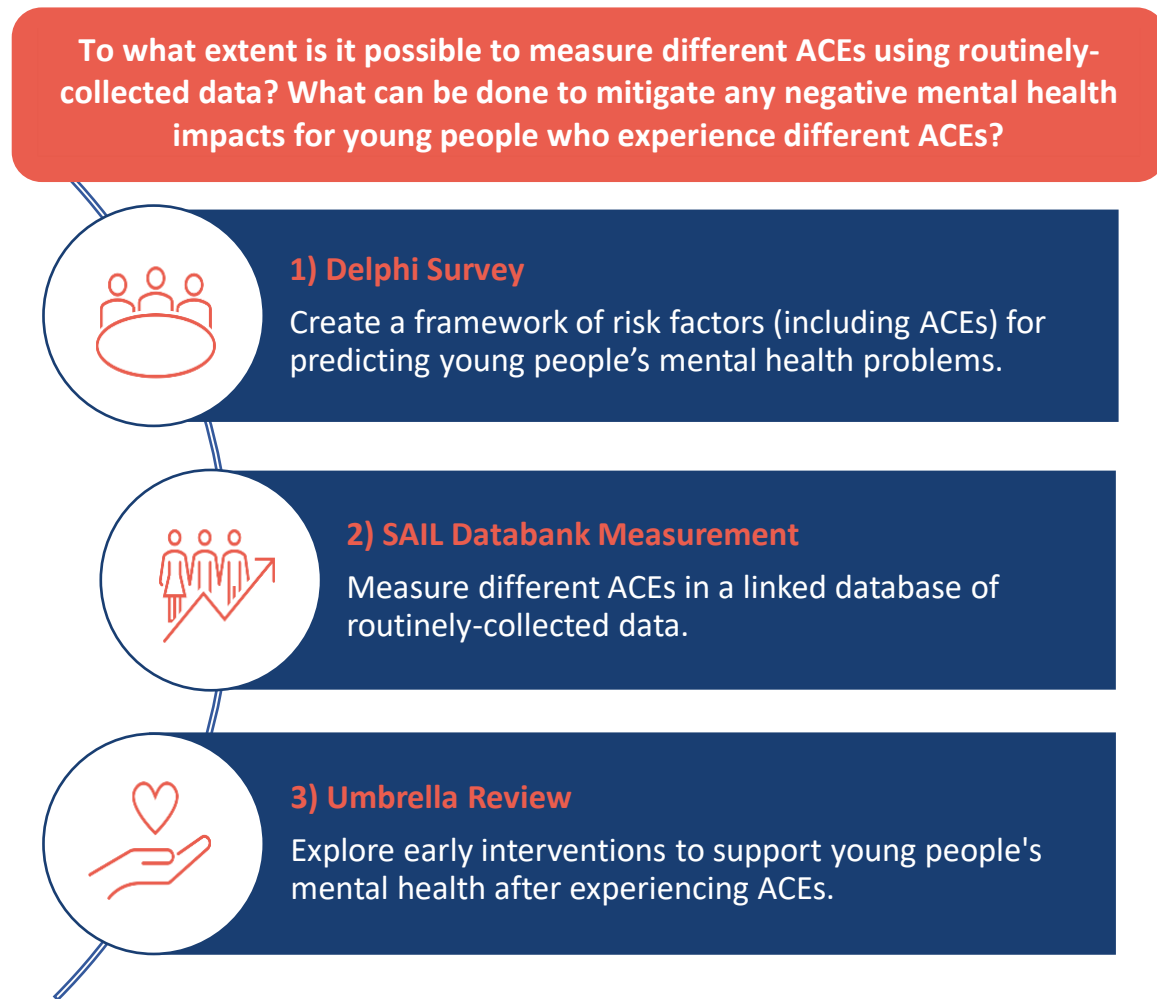
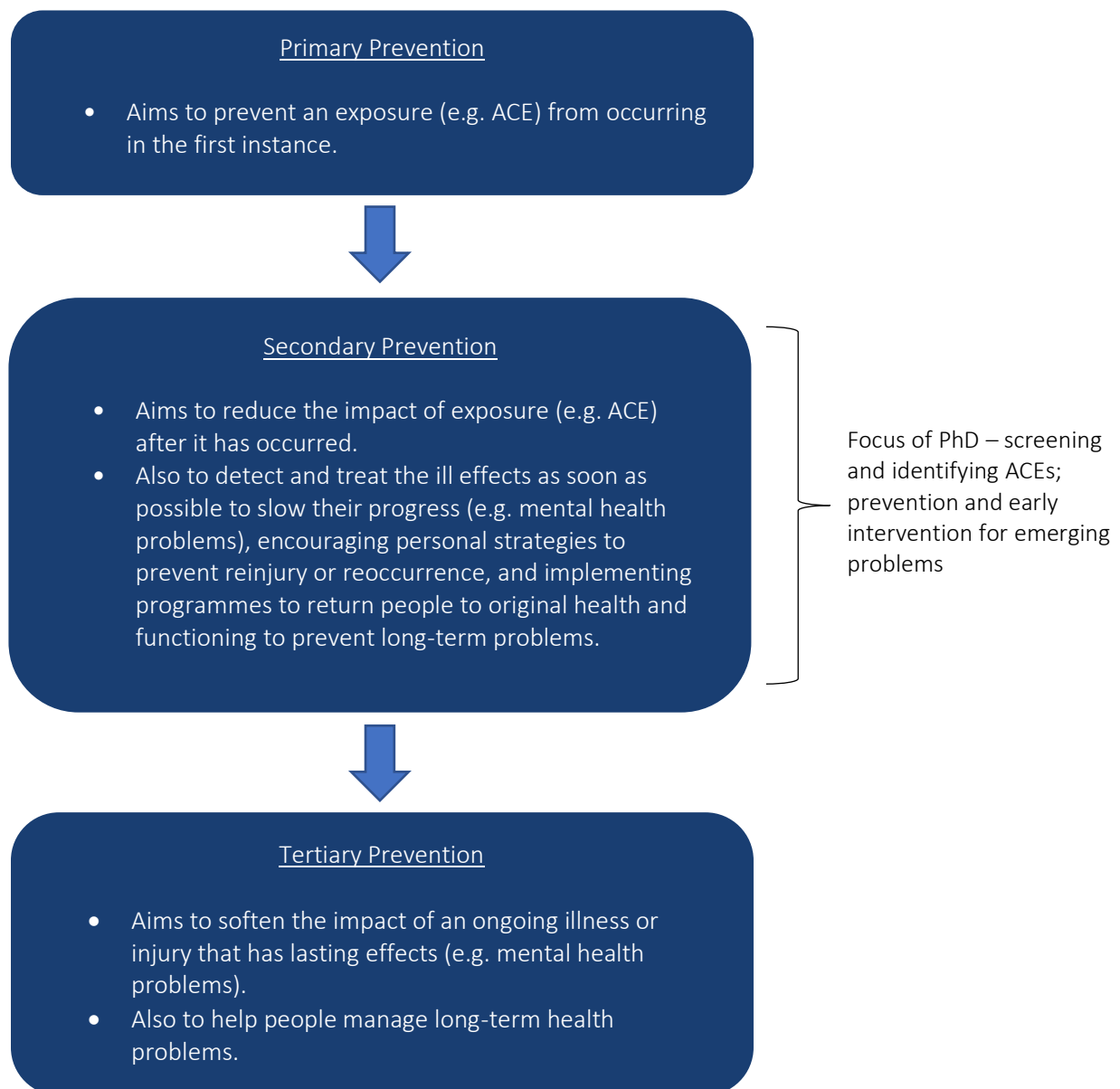


Figure 5: Diagram to show the project scope in the wider context of ACE prevention



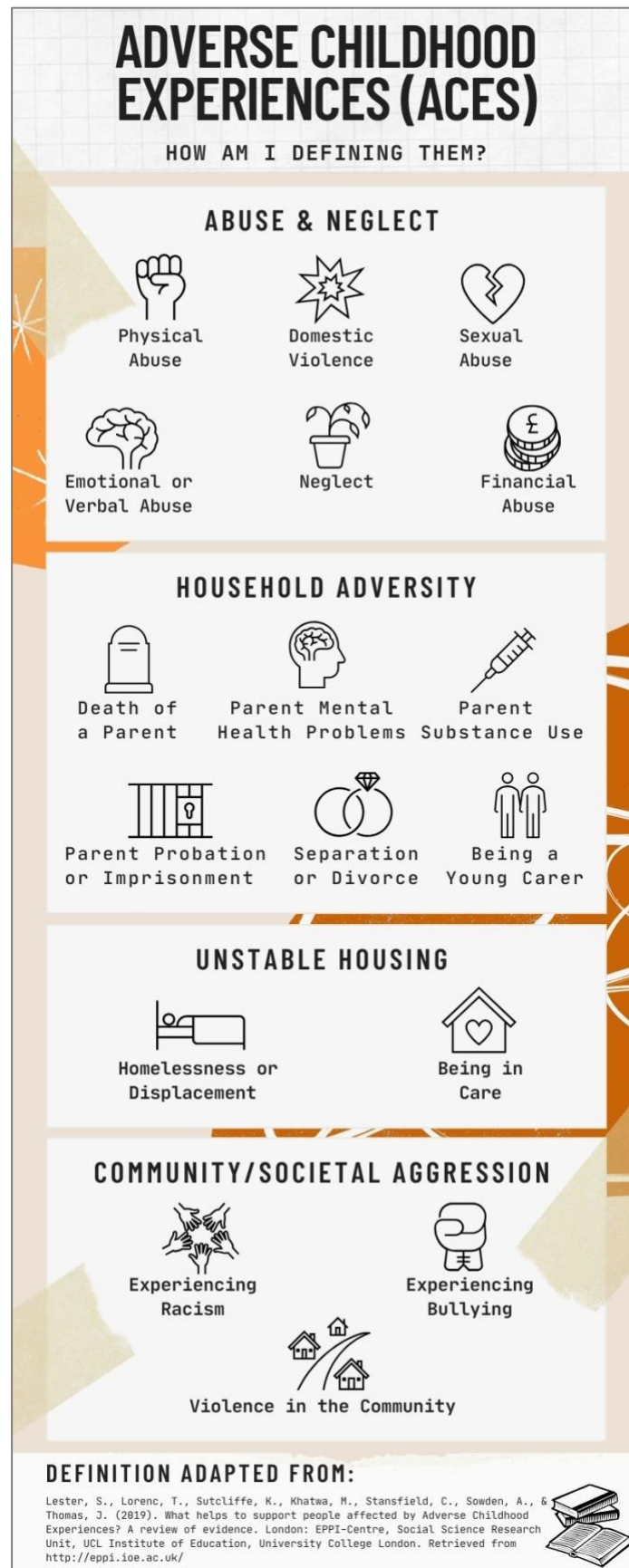
3 Chapter 3: Defining Adverse Childhood Experiences (ACEs)

3.1 Definition for PhD

The definition of ACEs used in this PhD was adapted from the work of Lester, Lorenc and colleagues (Lester et al., 2019; Lorenc, Lester, Sutcliffe, Stansfield, & Thomas, 2020). For the purposes of this thesis, ACEs consisted of the experiences listed below (and also visually shown in the infographic in Figure 6):

- Abuse and neglect:
 - physical abuse
 - sexual abuse
 - emotional or verbal abuse
 - financial abuse
 - witnessing or experiencing domestic violence
 - neglect
- Household adversity, where a parent or guardian:
 - is in prison or on probation
 - has a mental health problem
 - abuses alcohol or drugs
 - is separated or divorced
 - has died
- Involvement with child protective services (CPS) or living in care
- Homelessness or unstable housing (including asylum-seeking status or displacement due to conflict)
- Experiencing bullying
- Experiencing racism
- Experiencing violence in the community
- Being a young carer

Figure 6: Infographic of ACEs definition



Credit: created with Canva
<https://www.canva.com>

3.2 Background to definition choice

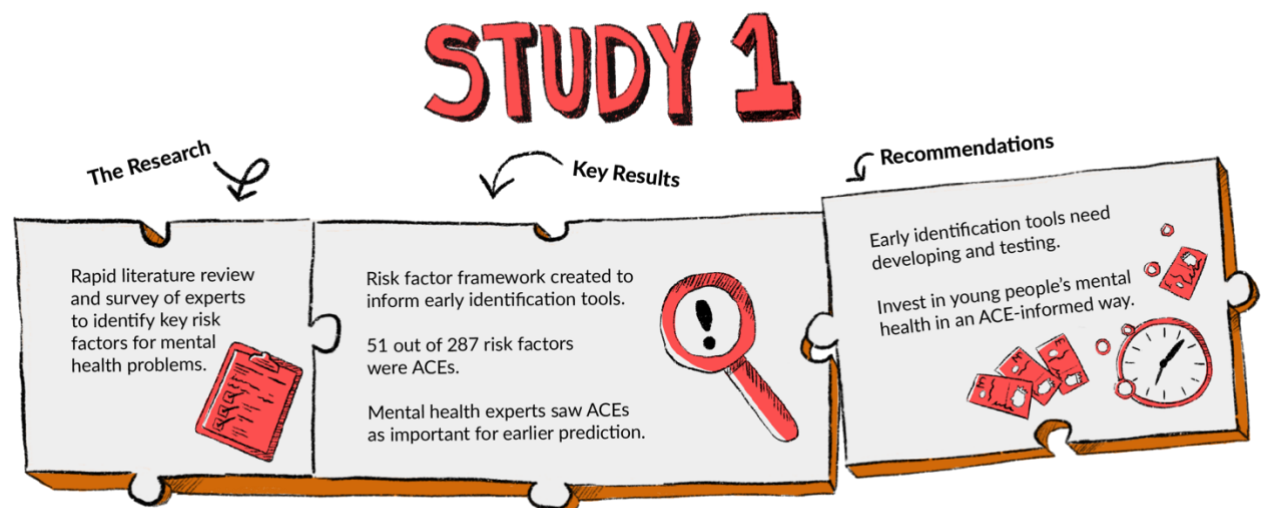
In the seminal study which first popularised the term ‘ACE’, Felitti and colleagues (1998) defined seven categories of ACE, consisting of three categories relating to childhood abuse (namely ‘psychological abuse’, ‘physical abuse’, and ‘contact sexual abuse’), as well as four categories of exposure to household dysfunction (namely ‘exposure to violent treatment of mother or stepmother’, ‘exposure to substance abuse’, ‘exposure to mental illness’ and ‘exposure to criminal behaviour’). In this study, ACEs were confined to the first 18 years of life and were recorded in a binary way (i.e. exposed to a category of ACE or not), without measuring the frequency or severity of exposure.

Building on this work, in a recent umbrella review and extended report (Lorenc et al., 2020; Lester et al., 2019, respectively), ACEs were defined as physical, sexual or emotional abuse; neglect; domestic violence in the home; homelessness or living in care; parental mental health problems or substance abuse; and parents who are absent through imprisonment, separation or death. Lester and colleagues (2019) definition of ACEs adopted the original ACE study’s definition, and extended this based on more recent research and discussions with key organisations. As such, it now includes young people affected by parental bereavement and neglect, and looked-after children (based on Allen & Donkin, 2015), as well as homelessness (based on discussions with the UK Department of Health and Social Care policy teams).

I chose to adopt this definition by Lester, Lorenc and colleagues because it provided more comprehensive coverage of ACEs than the original ACE study as it included other potentially vulnerable groups, such as looked-after children or homeless children. Furthermore, this definition choice was also a pragmatic one, as I would be updating the umbrella review by Lester, Lorenc and colleagues (2019) when I explored interventions to mitigate the mental health impact of ACEs.

However, I also modified this definition to include experiences of ‘bullying’, ‘racism’, ‘community violence’ and ‘being a young carer’ because of the significant evidence that these experiences are associated with mental health problems (Arseneault, 2018; The Philadelphia ACE Project, 2019; Van Niel, Pachter, Wade, Felitti, & Stein, 2014; Scottish Government, 2017, respectively). In addition, I chose to add ‘financial abuse’ to the category of ‘abuse and neglect’ because social services record this category of abuse (Welsh Government, 2024), which I learned when I carried out measurement of ACEs in the SAIL Databank (described later).

4 Chapter 4: A Delphi Study of Risk Factors for Mental Health Problems



Credit: designed by Nifty Fox Creative, 2024.

4.1 Declaration of contributions

The work in this chapter was carried out as part of a team (the Timely team, led by Dr Anna Moore). The Delphi project had begun before my PhD started, with Dr Moore developing the project idea, securing funding and co-drafting the protocol. Dr Shabina Hayat completed the ethics applications and amendments, and Dr Moore and Philip Lütgerath carried out the initial risk factor extraction (through a rapid review and discussion with clinicians/professionals). Under the supervision of Dr Moore, Dr Hayat and I compiled the initial theoretical framework of factors. Data extraction from literature in subsequent rounds was carried out by Dr Hayat, Emily Brewis and me. Survey development and question formation was carried out as a team, guided by our steering group. Each round of the survey was translated into its online format by psychology placement students, Yi Zhang and Emily Brewis. Dr Hayat, Yi and Emily carried out participant recruitment. Quick turnaround analysis for early rounds was conducted by Dr Moore, Dr Hayat, Yi Zhang, Tara Ramsay-Patel, Vahgisha Thirugnanasampanthan, Emily Brewis and I. Charlotte Burdge carried out brief data entry at a later stage. Dr Moore, Dr Hayat and I wrote the summary report for participants for Round 1, and I wrote the summary reports for subsequent rounds. Placement students were initially supervised 1:1 by Dr Hayat, and then by me when Dr Hayat left the team; additional supervision was given in team meetings with Dr Moore. When Dr Hayat left the team, I took over the general project management of the Delphi study, supervised by Dr Moore. Ryan Crowley and Dr Alisa Anokhina provided ad-hoc programming support. I carried out the analysis presented in this chapter, with invaluable statistical and programming support from Dr Rachel Sippy (in particular in the development of code to clean the data, rank risk factors and create heat maps). Nicole Marshall redid the heat maps for the main framework and reformatted the framework itself, all presented in the chapter appendix. All work on ACEs (including creation of visualisations) was carried out by me.

This work is being written up into the following manuscript:

Parkin, K., Crowley, R., Sippy, R., Hayat, S., Zhang, Y., Brewis, E., Marshall, N., Ramsay-Patel, T., Thirugnanasampanthan, V., Skinner, G., Fonagy, P., Brayne, C., & Moore, A. (2025). *Development of a Risk Factor Framework to inform Machine Learning Prediction of Young People's Mental Health Problems: A Delphi Study* [Manuscript in preparation]. Department of Public Health and Primary Care, University of Cambridge.

4.2 Chapter overview

The work in this chapter sought to compile and refine a framework of risk factors, including ACEs, for earlier prediction of childhood mental health problems. This framework would form a theoretical ‘wish list’ of risk factors to be identified within routine data sources, and tested in the development of risk prediction models for young people’s mental health problems. Here, I present work on a rapid review and Delphi process which was used to iteratively build consensus among a panel of experts about the final framework of risk factors, including domain groupings and prioritisation of risk factors. Subsequent sections of the thesis explore the extent to which these risk factors, especially ACEs, can actually be measured in routinely-collected data. This chapter’s work formed a roadmap of which factors (aka variables) to try to extract from routine data sources and include in early identification models.

4.3 Introduction

The fields of psychiatry and public health are converging towards primary preventive approaches, rather than simply seeking to treat problems when they arise. Much prevention is effected through societal action, but as well as this there is an interest in individualised approaches, as illustrated by calls for evidence-based screening programmes. Through precision medicine, researchers and clinicians seek to better match proven interventions to the individuals with whom they interact clinically at earlier stages of either risk or disorder manifestation (Baune, 2019).

The present study forms part of the larger programme of work linked to the ‘Timely’ project. As described in the thesis introduction, in this programme of work, a linked database called CADRE is being constructed consisting of routinely-collected data. An important aspect of linked database development involving routinely-collected data includes establishing data dictionaries. The Timely team aims to build a database which is useful for predictive technology in childhood mental health, however, there remains no consensus on which variables are important for predicting mental health problems in young people. To inform the building of CADRE, we undertook an evidence-building and refinement process to identify the key variables (or risk factors) of interest. This involved a rapid literature review, discussions with professionals, and development of a framework of risk factors, followed by a Delphi study to refine this framework. A Delphi study is a multi-stage survey, consulting a group of experts in a particular field through an iterative process, to build consensus on an issue.

4.3.1 Background to the problem and a gap for early identification tools

As noted previously, at present, very few prediction tools are available for clinical application within psychiatry or mental health; this is for a variety of reasons including model accuracy, lack of availability of relevant parameters within routinely-collected linked databases (where these exist), data quality issues, and implementation challenges, amongst others. However, some prediction tools exist in research settings (Chekroud et al., 2016; Hossain et al., 2019). Currently, early identification relies on young people or their caregivers presenting to professionals like GPs, and increasingly teachers or others without mental health expertise. Following this, they may be assessed for mental health problems in specialist children's mental health services (stem4, 2019). However, some people are mistrustful of these professionals or have reduced access to services, thus exacerbating health inequalities (Kreps, 2017; McFadden et al., 2018; Whitley et al., 2006). Furthermore, under the current stepped-care approach, young people have to become more unwell and/or experience greater distress before they can receive more support.

In contrast, through an early identification approach, at-risk young people could be identified sooner and offered proportionate support, if required. Though trial evidence is still needed to prove this one way or another, this method of early intervention may lessen the distress of young people and their families. It also has the potential to be more effective in that young people could receive support before mental health problems become well-established and have ripple effects on important areas of a young person's life, such as schooling, social relationships, lifestyle habits, and employment prospects (Early Intervention Foundation, 2018, 2021). Though early identification could definitely be argued to pose a short- to mid-term resourcing challenge, whereby more young people are identified who need support, this does also reflect a true demand which should be addressed. Furthermore, in the longer-term, early identification and intervention may be more effective and cost-effective than later treatment (Heckman, 2012). However, until we have mechanisms to enable early identification, we cannot easily carry out research to understand whether early intervention works or not. As such, we need to create the facility to identify young people early as a first step to understand the value of early intervention.

4.3.2 The present study

In order to be robust enough for clinical use as a decision-support tool, risk prediction models (which can become early identification tools when modified with features like a user interface, and then signed off with appropriate certification) need to be based on a prior understanding of how important each variable might be and how these variables relate to one another. As such, it is useful to have a

pre-defined expectation (or theoretical framework) of how you might expect variables, in this case ‘risk factors’, to interact. Most previous risk prediction models have not been sufficiently robust for use in clinical settings, in large part because the results derived from some machine learning methodology cannot be interpreted in a meaningful way to make clinical decisions (Meehan et al., 2022; Rudin, 2019). For example, these approaches can be opaque, and it can be unclear which factors are being used as predictors within the models.

In a systematic review of over two decades of research on clinical prediction models in psychiatry, Meehan and colleagues (2022) noted that:

“94.5% of developed prediction models were deemed to be at high risk of bias [emphasis added], largely due to inadequate or inappropriate analytic decisions... Several predictor selection strategies utilized by these studies were also prone to bias. From 220 model development studies, only 8.6% (19/220) selected candidate predictors a priori based on existing research evidence, clinical knowledge, or previous models, which minimizes the risk of bias [emphasis added]”.

As such, in order to improve the likelihood of the Timely early identification models being fit for clinical use, we first developed a prototype theoretical framework to group risk factors, and then sought feedback on this framework from experts in childhood mental health, through a series of online questionnaires, known as a Delphi survey. This Delphi process also provided a forum to prioritise the importance of various risk factors for predicting young people’s mental health problems. This prioritisation exercise was essential to provide a starting point to establish which of the thousands of factors within the CADRE database should be prioritised for data extraction and inclusion in prediction model development. This was especially important as some variables would be in unstructured data only (e.g. free-text notes), requiring the development of data extraction methods known as natural language processing (NLP). NLP algorithm development is incredibly time- and resource-intensive so the risk factor prioritisation exercise would provide a sensible hierarchy to guide the Timely team’s efforts. Furthermore, the framework of risk factors would provide means for rapid innovation in clinical informatics and mental health; it would do so by giving clinical insights to machine learning experts who may not have clinical expertise in what variables may be relevant predictors of childhood mental health problems. Finally, the Delphi study provided a means by which to make decisions about the developing CADRE database and focus resources on the most important areas when carrying out resource-intensive tasks (such as standardising and operationalising the data, and addressing missingness and data quality).

For the purposes of this thesis specifically, the rapid literature review and Delphi process provided a means to understand where ACEs fit amongst other potential predictors of mental health problems. The process resulted in an extensive list of potential predictors, and allowed exploration of the importance of ACEs compared to other risk factors. Furthermore, insights were gleaned into the timing of ACEs, i.e. when in a child's life course exposure to ACEs may be particularly detrimental to mental health outcomes, according to the opinions of a select panel of experts. This latter outcome generates testable hypotheses that move beyond simple ACE counts alone, which have known limitations (Lacey & Minnis, 2020; Reidy et al., 2021), and provides a more nuanced understanding of ACE exposure. Going beyond whether or not ACE exposure has occurred, and to how many categories of ACE, this work enabled exploration of the possible importance of exposure timing too.

4.3.3 Addressing inbuilt biases and reducing health inequalities

It is a fact that models are only as good as the data on which they are based. Furthermore, biases in data collection and representation are known to negatively affect data quality, exacerbating health inequalities for certain groups (Knight et al., 2021). This means that it may be harder to identify mental health problems in young people from certain under-served groups because data are poorer for these groups. Knight and colleagues (2021) highlighted that inbuilt racism and bias need to be considered and addressed at all points of the data pipeline, and our work sought to incorporate this knowledge. In order to try to address some of these inbuilt biases when constructing CADRE and subsequent early identification tools, this Delphi study sought to explicitly ask about risk factors which are especially salient to under-served groups, and to include participants who either identified as being part of some of these groups or who were more familiar with them. Though this cannot fully address the concern, we hoped this would go some way to build fairer, more inclusive early identification tools. This study sought to include perspectives from a broad range of experiences and gather expert guidance on factors relating to such groups, variously described as disadvantaged, minority, 'under-served' or 'hard-to-reach' groups.

4.3.4 Aims

The aims of this study were to:

- gain feedback on the validity of a prototype theoretical framework of risk factors for young people's mental health problems;
- identify any key risk factors missed from the framework;

- identify where in the life course exposure to each risk factor would be particularly important for leading to mental health problems;
- identify which domains would be most important for prediction of young people's mental health problems;
- create a prioritised list of risk factors for data extraction from the CADRE database (within structured data);
- create a prioritised list of risk factors for NLP algorithm development¹ (to extract risk factors from unstructured data);
- gain a diverse range of expert perspectives in order to minimise health inequalities created or exacerbated by the study and subsequent early identification tools;
- identify any key risk factors which were unlikely to be present in the current CADRE data sources, thus highlighting additional databases of value and facilitating data-sharing discussions with potential data providers.

In addition, my personal aims were to:

- understand the many important risk factors for young people's mental health problems and risk prediction models, of which ACEs are some;
- understand how ACEs fit into this picture among other non-ACE risk factors.

4.4 Methods

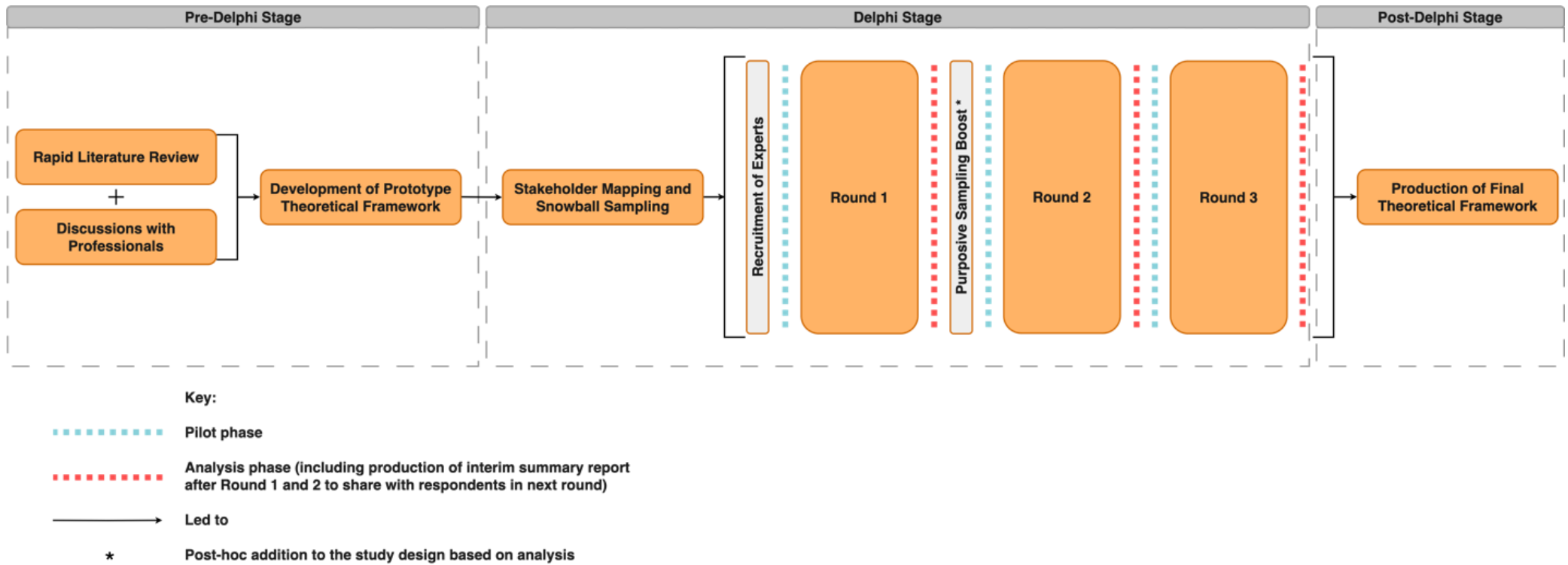
In order to draw on a wide range of expertise in young people's health and wellbeing, and to iteratively refine a framework of risk factors which could be useful to those in the field, we chose a consensus-building method known as a Delphi study. The Delphi method was chosen because it is designed to reach a group decision or opinion by surveying a group of experts on a topic (Barrett & Heale, 2020). Consensus is reached over a series of rounds, where each round is informed by responses from the same experts in the previous round. Experts are presented with their previous responses, plus the anonymised responses of other respondents, allowing them to reflect on this information when they make subsequent responses and adjust their opinion accordingly. To this end, this allows for multiple

¹ Natural Language Processing (NLP) can be used to explore unstructured (free-text) data, which may be a rich source of information on a young person's context. For example, an NLP algorithm for the term 'domestic violence' may search for exact matches but also instances of related terms such as 'hit', 'slap', 'kick', 'strangle', 'punch' and so on, along with proximity searches like the word 'violence' in close proximity to the word 'home'. Though, in practice, the algorithm is likely to be much more complex than this. Developing NLP algorithms to extract specific risk factors is a laborious and resource-intensive task, so a prioritised list of factors was needed to inform future resource allocation.

expert views to be considered whilst minimising the impact of the ‘halo effect’ where views from dominant or high-profile experts are given priority among the participants, which can happen in workshops or focus groups (Barrett & Heale, 2020). The developers of the Delphi method noted that it *“appear[s] to be more conducive to independent thought on the part of the experts and to aid them in the gradual formulation of a considered opinion”* (Dalkey & Helmer, 1963).

In contrast to focus groups or one-off interviews, the Delphi method facilitates reflection on an opinion and allows the study to evolve over time based on earlier findings, potentially leading to a more nuanced and considered answer to a research question or questions. This methodology also allowed us to seek expertise from a broad range of disciplines relating to childhood mental health and collate these views. Furthermore, the online and anonymised nature of the survey meant it was less prone to overemphasis of certain views to the detriment of other expert views. Finally, the online format was feasible during the COVID-19 pandemic, whereas an in-person workshop methodology would have been impossible. Figure 7 provides an overview of the different study stages. These stages are then described in detail in the following sections.

Figure 7: Diagram to illustrate stages of the study



Credit: created with draw.io (<https://app.diagrams.net/>).

4.4.1 Development of the prototype theoretical framework of risk factors

A rapid review of published literature was carried out in order to identify risk factors pertinent to the development of mental health problems in young people. We defined a 'risk factor' as any factor that was predictive of, or associated with, the development of mental health problems; these did not need to be causal factors. These risk factors were indicators (or variables) we would want to test in risk prediction models, forming a sort of theoretical 'wish list' of variables. The actual predictive strength (or lack thereof) of each factor will be explored by the Timely team in future model development, outside the scope of this thesis. To be included in the prototype theoretical framework, risk factors had to be from studies rated by the reviewer as moderate or higher quality during their quality assurance process, have a significant association with mental health problems, and have a moderate or larger effect size according to the paper from which they were extracted. As such, any risk factors with only a weak effect, for which there was no significant association, or published in a study deemed to be of low-quality evidence were excluded.

Risk factors which were highlighted through discussion with clinicians and professionals were also included. For example, colleagues from community paediatrics indicated how important patterns of service use may be for predicting young people's mental health problems, such as low attendance at routine appointments like vaccinations and dental checks, or conversely, frequent attendance at emergency and community health services.

After compiling a list of candidate risk factors, these were grouped into domains and life course stages, forming a matrix. The domain grouping was an iterative process whereby we initially built on the biopsychosocial model, then added further groups or collapsed groups together based on identification of more risk factors, and further discussion with the research team, extended team, and clinicians/professionals.

4.4.2 A note to the reader: ACEs versus all Delphi risk factors

Only a subset of the risk factors included in the Delphi framework were ACEs. As mentioned, the Delphi project was part of a wider piece of work to understand the many risk factors for developing mental health problems, of which ACEs were only part of the picture, but are the focus of this thesis. As such, this chapter draws attention to the findings on risk factors classified as ACEs (by the definitions used in this thesis), but the overall findings for all risk factors in the Delphi study are also reported, thus putting ACEs in the context of other important predictors of mental health. Throughout the chapter, it is indicated when ACEs alone are being discussed, or all Delphi risk factors, including ACEs.

Presentation of both of these helps to situate ACEs as important, but far from the whole story when trying to build risk prediction models for childhood mental health problems.

4.4.3 Identifying experts in the field

To identify participants to complete the Delphi survey, a stakeholder mapping exercise was carried out, followed by a 'snowball sampling' approach to identify experts from a range of disciplines and fields relevant to mental health. This began with experts the team was already aware of and we then asked them to identify other experts in relevant fields.

In Round 2, we also purposively sampled to identify experts from fields poorly represented in Round 1 by asking current respondents to identify colleagues or professionals who could address gaps and also by searching ourselves on online academic forums (such as university and departmental websites). We specifically sought better representation from: 1) the field of genetics and biomarkers of mental ill-health; and 2) professionals from ethnic minority backgrounds in order to help with our aim of addressing health inequalities in our study design and subsequent database build. In addition, we sought expertise from different geographical regions, including contacting international experts, trying to mitigate against a Cambridge- or UK-centric sample. Respondents were asked to provide information on their roles and years of experience.

No new participants were added at the Round 3 stage; invitations for Round 3 were sent to the same individuals as Round 2. Thus, all individuals contacted to take part in Round 3 had also taken part in Round 1 and/or 2. As such, demographic information was not collected again.

4.4.4 Running the survey

The Delphi study was carried out online and run over three rounds, with each round focused on a different aspect of refining the prototype theoretical framework. Data collection occurred between June 2021 and May 2022 (Round 1: June – August 2021; Round 2: October – November 2021; Round 3: April – May 2022).

A steering group, made up of experts in childhood mental health, was consulted during the development of the Delphi survey in order to advise on its content; steering group membership included experts such as Prof. Peter Fonagy and Prof. Tamsin Ford.

Each round was piloted by two academics outside the study team in order to check the questions, gauge time to complete the survey, assess survey logic, and identify any other issues. The survey link was then emailed to participants for completion, with a few weeks to complete each round and reminders sent towards the closing deadline. As an incentive to participate, respondents were given the option to provide their email address in the final round to be entered into a prize draw for £50 of vouchers. Rounds 1 and 2 were hosted on the survey platform REDCap (Research Electronic Data Capture) (Harris et al., 2019, 2009), and Round 3 was hosted on the platform Qualtrics XM (Qualtrics, 2005). The change of platform was due to unanticipated functionality requirements and user-friendliness of the latter platform for our purposes.

4.4.5 Specific aims of each round

Round 1:

- Sought to establish consensus on the overall approach, the framework domains and the life course stages used to group the risk factors.

Round 2:

- Sought to establish consensus on which domains were most important for prediction of young people's mental health problems, and identify where in the life course exposure to each risk factor would be particularly important for leading to mental health problems². Respondents were also asked to add any risk factors they felt had been missed in the framework. Finally, they were asked to review the changes made from Round 1 and provide feedback on whether the changes had addressed issues with the framework structure.

Round 3:

- Sought to rank the risk factors within domains in terms of how important they each were for predicting young people's mental health problems (to be used to inform NLP algorithm development). Respondents were also asked to indicate where in the life course exposure to the new risk factors from Round 2 would be most important for mental health problem development.

4.4.6 Methodology: acceptability of the overall approach, domain groupings, life course stages and use of individual risk factors (Rounds 1 and 2)

Respondents were asked to rate the acceptability of the overall approach to the framework, the domain groupings, life course stages and use of individual risk factors on a scale of 1-10. For these questions which required a group consensus to be reached, a pre-defined threshold was set. The

² This question was added post-hoc to the Delphi study based on advice from our steering group.

median score from respondents for each question had to be ≥ 0.7 (or 70%) in order to conclude consensus had been reached. Where this was not reached, modifications were made to the framework as required, anonymised feedback was presented to the group in Round 2, and the question was repeated to see whether the modifications satisfied the group.

4.4.7 Methodology: ranking of domains (Rounds 2 and 3)

Respondents ranked the eight domains in order of importance for predicting childhood mental health problems; they were only presented with the domains they said they were able to rank. An average rank was calculated per domain in order to rank the domain's importance for prediction. A median (rather than mean) score was calculated for the average in order to mitigate against outliers. The same pre-defined threshold of ≥ 0.7 (or 70%) was used to conclude whether consensus was reached.

The respondent sample was skewed towards certain specialties (e.g. psychology and psychiatry), and we questioned whether this would mean certain domains received higher rankings by virtue of their alignment with respondents' expertise. A chi-square test was used to explore this. This test generally did not indicate a significant relationship between being from a certain specialty and whether or not respondents chose to rank a domain. Following a team discussion, we tentatively concluded it was legitimate not to weight the rankings given by respondents from less represented fields (such as genetics), and unweighted ranks are presented in the Results section.

4.4.8 Methodology: life course stages of greatest salience (Rounds 2 and 3)

Respondents were presented with a matrix of risk factors from the domains they were able to comment on. This was predominantly completed in Round 2, but the process was repeated in Round 3 for new risk factors added following Round 2. Respondents were asked to indicate which individual life course stages they thought were most important for predicting the development of mental health problems (i.e. when does exposure matter most for developing mental health problems?). To save them time when responding, an option was provided to tick that 'all life course stages' were important if they believed this to be the case, rather than manually ticking each stage (because there were over 250 factors in total if they chose to comment on all). Of note, if respondents ticked 'all life course stages' and also manually ticked individual life course stages, the latter was taken as their vote because they had chosen to emphasise particular stages.

Based on the responses, the proportion of importance per life course stage per risk factor was calculated. This was visualised as 'heat maps' to illustrate where in the life course exposure to each risk factor would be especially important for predicting mental health problems.

4.4.9 Methodology: ranking of risk factors (Round 3)

Respondents were asked to rate their perception of the importance of each risk factor from 0-100 using a slider. Respondents indicated which domains they felt able to rate factors for, and then asked for their level of expertise in the domains they had chosen to rate. The expertise was self-rated on a scale of 0 – 4 where: 0 = None; 1 = Basic; 2 = Intermediate; 3 = Advanced; 4 = Expert. Respondents were only presented with risk factors from the domains they indicated they were able to comment on, and they could also indicate if they were unable to rate a specific risk factor within these domains. In the final risk factor rankings, only ratings from respondents with self-rated expertise of 2 or above on that particular domain were included. This excluded ratings from respondents who rated their expertise as 'none' or 'basic'. This was to ensure the final risk factor rankings were based on expert opinion as far as possible.

For each individual respondent, we calculated how many points they allocated throughout the exercise, and then what proportion of these points were allocated to each given risk factor. Then, for each risk factor, we calculated the mean rating given by all respondents who were able to comment on that factor.

This resulted in ranked or prioritised lists of risk factors within each domain. Of note, this gave the relative importance of factors within domains and could not be used to compare the importance of factors across domains because different respondents commented on different domains.

4.4.10 Data analysis and visualisation

A mix of quantitative and qualitative methods were used for analysis, as required by each survey question. Quantitative analysis was performed in Excel and R. Qualitative feedback was explored using Excel and NVivo, in order to draw out themes and sentiment from free-text comments.

Insights were integrated from each round into the development of the subsequent round, creating an iterative process of refinement of the prototype theoretical framework. At the start of Rounds 2 and 3 of the survey, a summary of feedback and findings from the previous round was included, as well as any changes made and a rationale where we did not act upon feedback. This feedback sharing is an

important part of the Delphi methodology, allowing respondents to first form opinions individually, then to subsequently consider the thoughts of the wider group, and re-deliberate to reach a shared decision.

Some questions were part of this iterative process of refinement and deliberation (e.g. domain rankings; life course groupings), and involved reaching an a priori consensus threshold of ≥ 0.7 , whereas others were stand-alone questions, and asked only in one round (e.g. indicating the importance of each life course stage per risk factor; rating the importance of each risk factor within domains).

With regard to data visualisation, tables were created in R and visualised/formatted in Excel. R, including the ggplot2 package (v 3.4.0; Wickham, 2016), was used to produce heat maps for all risk factors, and the web-based tool Flourish (Canva UK Operations Ltd, 2018) was used to reproduce heat maps for ACEs specifically.

4.4.11 Ethical approval

The study was reviewed and approved by the University of Cambridge Psychology Research Ethics Committee (REC Ref: PRE.2021.028).

4.5 Results

The results are presented in two sections. Firstly, the demographic data and the results on the whole framework of risk factors are presented, of which ACEs are a subset (see Page 36 onwards). Of note, the demographic data relate to everyone, not just those who could comment on ACEs. Secondly, the results on ACEs alone are presented (see Page 48 onwards). Though ACEs are the focus of this thesis, the broader results are presented first in order to aid interpretation and provide wider context to the ACE-only section.

4.5.1 Results – Part 1: broader results on the whole framework of risk factors and demographic data

4.5.1.1 Initial prototype theoretical framework

Following the initial literature review, 193 risk factors were extracted from publications, including systematic reviews and independent policy or research reports. These were compiled into groupings, forming the ‘Prototype Theoretical Framework’ which provided the first base for the Delphi consultation. Before suggestions from the survey respondents, the overarching domains initially

consisted of the following: Environmental (including exposures); Social (including safeguarding and adverse childhood experiences); Behavioural; Educational; Biological (non-pathological); Clinical (physical health); Clinical (psychological and mental health); and Patterns of Service Use. The original life course stages were: Parental; Pregnancy; Birth and Infancy (0-1 year); Childhood to Early Adulthood (1-25 years).

4.5.1.2 Participant recruitment and demographics

Initially, 228 individuals were invited to participate in Round 1 of the study, of whom 82 (36%) agreed. Of these 82 potential participants, 50 (61%) completed the online consent form and 32 (39%) failed to respond. 39 of the 50 who consented to participate actually completed Round 1 of the survey (which was defined as completing at least one survey question, not including consent or demographic information). In Round 1, the mean years of professional experience of respondents was 21.24 years. The years of experience did not differ significantly by gender or sector, but it was not possible to test by ethnicity due to subgroups with small sample sizes.

Based on the demographics of respondents in Round 1, we had not reached as diverse a respondent sample as desired. In particular, there was an under-representation of experts from ethnic minority backgrounds, which we believed to be important for mitigating health inequalities in the data pipeline, and also from the field of genetics and biomarkers, which we believed to be important for expertise coverage. As such, purposive sampling was carried out in Round 2 (as described in the Methods section 4.4.3). After this, representation from under-represented ethnic groups somewhat increased, though not as much as we would have liked. Representation from those with expertise in genetics and biomarkers did not improve. The mean years of professional experience of respondents was 20.35 years in Round 2. See Table 2 overleaf for a comparison of demographic data from Rounds 1 and 2, i.e. pre- and post-purposive sampling. No new participants were invited to Round 3. 29 people consented to take part in Round 3, of whom 25 (86.21%) actually did. Table 1 summarises how many respondents participated per round.

Table 1: Number of respondents who completed at least one question per round (i.e. classed as survey respondents)

Round	Number of respondents
1	39
2	55
3	25

Table 2: Demographics of individuals from Rounds 1 and 2 (i.e. pre- and post-purposive sampling) who completed at least one part of the survey

		N of respondents in Round 1 (%)	N of respondents in Round 2 (%)	Mean years of experience in Round 2 (standard deviation; SD)*
Gender	Men	13 (33.3)	13 (23.6)	24.8 (12.6)
	Women	26 (66.7)	33 (60.0)	19.3 (10.1)
	Non-binary/Third Gender	0 (0.0)	1 (1.8)	7.0 (N/A)
	Prefer Not to Say	0 (0.0)	1 (1.8)	10.0 (N/A)
	Unknown/Missing Gender	0 (0.0)	7 (12.7)	N/A (N/A)
Total (%)		39 (100)	55 (100)	
Ethnicity	White English, Welsh, Scottish, Northern Irish or British Irish	27 (69.2)	29 (52.7)	21.6 (11.2)
	White and Asian	1 (2.6)	0 (0.0)	N/A (N/A)
	Other White	10 (25.6)	14 (25.5)	21.3 (11.9)
	Indian	1 (2.6)	2 (3.6)	11.0 (1.4)
	Pakistani	0 (0.0)	1 (1.8)	21.0 (N/A)
	Other Asian	0 (0.0)	1 (1.8)	10.0 (N/A)
	Any Other Mixed or Multiple Ethnic Group	0 (0.0)	1 (1.8)	7.0 (N/A)
	Unknown/Missing Ethnicity	0 (0.0)	7 (12.7)	N/A (N/A)
Total (%)		39 (100)	55 (100)	
Sector**	Academia	18 (46.2)	19 (34.6)	20.2 (12.0)
	Clinical	18 (46.2)	23 (41.8)	20.1 (9.5)
	Non-Clinical Professional	2 (5.1)	3 (5.5)	19.0 (18.2)
	Education (Teachers)	4 (10.3)	4 (7.3)	22.0 (5.9)
	Other	4 (10.3)	4 (7.3)	26.5 (17.4)
	Unknown/Missing Sector	1 (2.6)	11 (20.0)	N/A (N/A)

Table 2 (continued): Demographics of individuals from Rounds 1 and 2 (i.e. pre- and post-purposive sampling) who completed at least one part of the survey

		N of respondents in Round 1 (%)	N of respondents in Round 2 (%)	Mean years of experience in Round 2 (standard deviation; SD)*
Specialty**	Behavioural Research	3 (7.7)	3 (5.5)	16.7 (5.8)
	Biomarkers Research	1 (2.6)	1 (1.8)	20.0 (N/A)
	Child and Adolescent Psychiatry	12 (30.8)	14 (25.5)	17.8 (11.8)
	Child and Adolescent Psychology	17 (43.6)	18 (32.7)	18.4 (9.8)
	Child Development	4 (10.3)	4 (7.3)	18.0 (6.3)
	Child Maltreatment/Trauma	8 (20.5)	8 (14.6)	23.5 (9.7)
	Child Psychopathology	7 (18.0)	7 (12.7)	20.4 (9.1)
	Social Sciences	2 (5.1)	2 (3.6)	13.5 (5.0)
	Genetics	1 (2.6)	1 (1.8)	11.0 (N/A)
	Education	8 (20.5)	8 (14.6)	21.5 (11.8)
	Social Care	4 (10.3)	3 (5.5)	22.0 (12.5)
	Other Local Authority Services	1 (2.6)	1 (1.8)	20.0 (N/A)
	Paediatrics	3 (7.7)	4 (7.3)	17.9 (7.9)
	Policy	1 (2.6)	1 (1.8)	21.0 (N/A)
	Prevention	3 (7.7)	2 (3.6)	17.0 (5.7)
	Public Health	1 (2.6)	1 (1.8)	21.0 (N/A)
	Other	3 (7.7)	6 (10.9)	22.2 (15.7)
	Unknown/Missing Specialty	0 (0.0)	10 (18.2)	N/A (N/A)
Role**	Administrative	0 (0.0)	0 (0.0)	N/A (N/A)
	Management	5 (12.8)	8 (14.6)	20.9 (5.1)
	Clinician	17 (43.6)	21 (38.2)	21.4 (11.0)
	Researcher	19 (48.7)	21 (38.2)	20.0 (11.4)
	Support Staff	0 (0.0)	0 (0.0)	N/A (N/A)
	Trained Professional	9 (23.1)	10 (18.2)	24.2 (13.6)
	Health Front Line	3 (7.7)	6 (10.9)	19.4 (5.4)
	Other	1 (2.6)	1 (1.8)	20.0 (N/A)
	Unknown/Missing Role	0 (0.0)	10 (18.2)	N/A (N/A)

*Average years of experience and statistics calculated from those who completed at least one part of the questionnaire.

N/A = Some sub-groups were too small and statistical analysis was not possible.

** Participants could tick more than one specialty; thus, results add up to more than the sample size.

4.5.1.3 Findings: overall framework approach (Rounds 1 and 2)

Round 1 sought feedback on the overall framework and approach taken; this included domains, life course groupings, approach to mitigating health inequalities, and approach to individual risk factors. Most respondents agreed with the overall approach, commenting that it was clear and easy to follow. The approach was described as ‘well organised, inclusive and engaging’. Respondents highlighted some limitations in the original framework, in particular the lack of interplay shown between individual, and wider societal and family risk factors and that the risk factors relating to inequalities were not well-represented.

Respondents rated their level of agreement from 1-10 in relation to the overall approach taken to the domains, life course groupings, inequalities, and individual risk factors. Table 3 provides an overview of the consensus results from Round 1. Consensus was reached with respect to all the included domains. When considering the life course stage approach taken, consensus was not reached regarding the life course stage 1-25 years, with the predominant view being that this was too broad. With regard to the acceptability of our approach to addressing inequalities and only considering individual risk factors³, respondents did not consider either approach acceptable.

³ This particular result should be interpreted with caution as it seemed to have been misunderstood by respondents. The wording incorrectly implied we were only interested in child-specific risk factors (e.g. sex, ethnicity, experience of abuse), and not their broader context. Yet, many of the risk factors in the framework did in fact relate to the child’s wider context (e.g. experiences of war and conflict). We were interested in how these child-specific and wider factors affected an individual child, but the nuance seemed lost in the question wording. To enhance clarity about our approach to individual factors, we incorporated Bronfenbrenner’s ecological model (Bronfenbrenner, 1979; Bronfenbrenner & Morris, 2006), illustrating levels of factors.

Table 3: Consensus results for each area consulted on in Round 1

		Number of respondents (N)	% consensus/ mean
Domains	Environmental (inc. exposures)	37	100.0
	Social (inc. safeguarding and ACEs)	35	92.1
	Behavioural	36	100.0
	Educational	38	100.0
	Biological (non-pathological)	37	94.9
	Clinical (physical health)	37	94.9
	Clinical (psychological and mental health)	38	97.4
	Patterns of Service Use	33	91.7
Life course stages	Parental	33	89.2
	Pregnancy	37	100.0
	Birth and Infancy (0-1 year)	36	94.7
	Childhood to Early Adulthood (1-25 years)	36	54.3*
Inequalities		39	68.5*
Individual risk factors³		39	47.9*

* Indicates question did not reach consensus

Following discussions between the team, and consultation with the steering group of experts, changes were made to the framework based on feedback in Round 1. These changes are summarised in Table 4. Any feedback from Round 1 which was not acted upon is summarised in Table 5, with a rationale for the decision.

Table 4: Feedback acted upon from Round 1

Suggestion	Changes made
Levels for individual risk factors	An amended version of the ecological model (Bronfenbrenner's model) was adopted, restructuring the theoretical framework to show different levels of risk factors i.e. individual-, family/caregiver- and society-level.
Increased granularity in life course stages	The life course stages were modified, creating a more granular approach, removing 'parental' as this was now incorporated within the new tiered structure (individual-, family/caregiver- and society-level risk factors). The new life course stages were chosen to fit key transitions (school and mental health services) and to reflect a developmental approach, recognising key stages and biological factors such as the onset of puberty. Amended life course stages were as follows: Pregnancy; Birth-2 years; 3-11 years; 12-17 years; 18-25 years.
Terminology for health inequalities	Following the NIHR INCLUDE guidance (NIHR, 2020), the term 'under-served populations' was adopted and used in subsequent rounds, instead of referring to those suffering inequalities.
Highlight factors relating to under-served populations	Feedback regarding our approach to highlighting risk factors most relevant to those from under-served populations indicated that while many of the risk factors appeared to be present, they were not well-highlighted in the framework. We also acknowledged that a risk factor may be relevant to both those from under-served populations and those not identified in that group. Although our initial approach was for each risk factor to appear in only one domain, it was decided the domain 'Factors Identified to be Particularly Relevant to Under-Served Populations' should be added. This new domain included the relevant risk factors for under-served groups (as well as the risk factor staying in its original domain too). The aim of this new domain was to highlight factors of greatest importance for certain populations and make these factors easier to assess collectively.
Respondent sample diversity	We had not achieved our objective of sufficient diversity of respondents in the Delphi panel. As this was considered an important aspect of the study, we decided to selectively recruit participants with the aim of improving the diversity of the panel.

Table 5: Feedback not acted upon from Round 1 and rationale for decision

Suggestion	Rationale for not acting upon suggestion
Include resilience/protective factors	To do due diligence with resilience/protective factors and be as rigorous as with risk factors, the lengthy process of factor gathering would need repeating (i.e. literature reviews and discussion with professionals). This was outside the practical scope of the project at this stage. However, many factors in the framework could act as either risk or resilience/protective factors depending on the context (e.g. sex, high IQ, single-parent family), and also depending on their presence or absence (e.g. the presence/absence of abuse).
Include networks or interactions between risk factors	The team planned to use the final framework to explore relationships between risk factors so did not want to hypothesise these further at this stage.

Following changes made based on Round 1 feedback (as detailed in Table 4), consensus was reached in Round 2 on all aspects of the overall framework approach. Selected qualitative feedback on the changes is shown in Table 6.

Table 6: Selected quotes from Round 2 respondents about alterations to framework from Round 1

Item	Quotes
Framework's overall structure	<i>"Welcome inclusion of life stages, particularly emphasising early years (Pregnancy and Birth-2 years) where risk factors will be very different from risks for example for 12-17 years."</i> <i>"The new structure does a good job to break down the post infant life stages and align them to pathways through the education system."</i> <i>"I think the comments in the narrative about the changed framework and what drove it e.g. ecosystemic approach and use of terms like underserved is really welcome and really strengthens it."</i>
Amended life course stages	<i>"These seem to correspond to major transition points in development"</i> <i>"I think this is a big improvement from the previous split."</i> <i>"3-11 is a big range but accept have to call the line somewhere so seems reasonable"</i>
Addressing inequalities	<i>"Really useful category. I am pleased to see that the study is addressing these social discrimination factors for under-served populations living in areas with disparity of opportunities and inequitable distribution of resources."</i>

Further suggestions were provided in Round 2; those which were acted upon are summarised in Table 7 and those which were not are shown in Table 8.

Table 7: Feedback acted upon from Round 2

Suggestion	Changes made
Missing under-served groups	Based on feedback that certain groups were missed, additional risk factors were added to the domain 'Factors Identified to be Particularly Relevant to Under-Served Populations'. To do this, the NIHR INCLUDE guidelines (NIHR, 2020) were used alongside suggestions from respondents. Risk factors were identified and included that were directly associated with being a member of one of these under-served groups, or where an individual's family or caregiver(s) were part of these groups.

Table 8: Feedback not acted upon from Round 2 and rationale for decision

Suggestion	Rationale for not acting upon suggestion
Standardise the risk factor granularity; amend overlapping risk factors	Respondents noted there was a mix of both general and highly specific risk factors (e.g. 'experience of past traumatic event' and 'trapped during earthquake'), as well as overlapping risk factors (e.g. 'unhealthy diet', plus 'high levels of ultra-processed foods in diet', 'high ratio of omega-6 to omega-3 fatty acids in diet', and 'low levels of omega-3 polyunsaturated fatty acids in diet'). However, this was because our methodology involved literature searches of risk factors and we felt unable to extrapolate beyond the risk factors directly measured in these papers so used the specificity stated in the source paper.

4.5.1.4 Findings: ranking of domains (Rounds 2 and 3)

With regard to ranking domains in order of predictive utility, the average rankings given by respondents in Round 2 for each domain are shown below in Table 9. After ensuring the final ranked list reached consensus in Round 3, the final results of the domain ranking exercise were as shown in Table 10. Of note, some domain rankings were tied.

Table 9: Averages and range of rankings for each domain, listed in the approximate order in which they were ranked in Round 2

Domain	Number of respondents able to rank (%)	Average ranking (median)	Average ranking (mode)	Range of rankings
Social and Environmental	33 (60.0)	1	1	1 – 5
Psychological and Mental Health	34 (61.8)	2	1	1 – 4
Education and Employment	23 (41.8)	4	3	2 – 6
Behavioural	24 (43.6)	4	4	2 – 7
Factors Identified to be Particularly Relevant to Under-Served Populations	18 (32.7)	5	5	2 – 7
Biomarkers	10 (18.2)	4	6	1 – 7
Patterns of Service Use	17 (30.9)	5.5	6	2 – 8
Physical Health	16 (29.1)	5	7	2 – 8

Table 10: Final ranked position of each domain after Round 3 in terms of importance for mental health prediction

Rank	Ranked position	Domain
1st	Median of 1	Social and Environmental
2nd	Median of 2	Psychological and Mental Health
Tied 3rd	Median of 4	Behavioural
Tied 3rd	Median of 4	Biomarkers
Tied 3rd	Median of 4	Education and Employment
Tied 6th	Median of 5	Factors Identified to be Particularly Relevant to Under-Served
Tied 6th	Median of 5	Populations
		Physical Health
8th	Median of 5.5	Patterns of Service Use

4.5.1.5 Descriptive results for consensus questions (Rounds 1 to 3)

For questions from Rounds 1 to 3 requiring a consensus decision, descriptive results are shown in Table 11.

Table 11: Descriptive results for questions requiring consensus to be reached

		Descriptive results			
		Number of responders (N)	Number of non-responders	Median acceptability rating (interquartile range; IQR)	Range of ratings
Question	Framework's overall structure*	42	13	8.0 (7.0, 8.75)	4 – 10
	Amended life course stages*	39	16	9.0 (7.5, 10.0)	4 – 10
	Addressing inequalities*	37	18	8.0 (7.0, 9.0)	2 – 10
	Domain ranking**	25	0	8.0 (7.0, 8.0)	4 – 10

* Responses for Round 2 (based on changes made after Round 1).

** Responses for Round 3 (based on ratings from Round 2).

4.5.1.6 Findings: life course stages of greatest salience (Rounds 2 and 3)

Based on Rounds 2 and 3, heat maps were made, indicating where in the life course respondents thought exposure to each risk factor was most important for the development of childhood mental health problems. These can be found in Appendix A.3 (Figure 24 to Figure 30, and Figure 31; factors from the main framework and those relating to under-served populations, respectively).

Table 12 illustrates the variation in the range of respondents able to comment on life course stages per domain. The domain with the highest median number of raters was the 'Psychological and Mental Health' domain, with a median of 30 raters. The domains with the joint lowest median number of raters were the 'Biomarkers' domain and the 'Factors Identified to be Particularly Relevant to Under-Served Populations' domain, both with a median of 6 raters.

Table 12: Number of raters per domain

Domain	Range of respondents	Median number of respondents	Interquartile range (IQR)
Social and Environmental	7 – 30	22.5	13 – 29
Behavioural	6 – 22	16	14 – 18
Education and Employment	6 – 21	18	14 – 20
Biomarkers	0 – 10	6	4 – 7
Physical Health	6 – 15	11	10 – 13
Psychological and Mental Health	14 – 32	30	28 – 31
Patterns of Service Use	7 – 13	9	7 – 12
Factors Identified to be Particularly Relevant to Under-Served Populations	3 – 14	6	6 – 6

4.5.1.7 Findings: ranking of risk factors (Round 3)

Based on feedback from Round 3, ordered lists of risk factors within domains were created. As a reminder, ratings were only considered from those with ‘intermediate’ or above expertise for each particular domain, based on a self-rated scale. Table 13 provides descriptive information about the number of respondents able to comment per domain and their self-rated expertise.

Table 13: Number of respondents per domain providing their self-rated level of expertise

Domain	N of respondents able to comment on domain (%)	N of respondents unable to comment on domain (%)	Expertise mean (SD)	Range of expertise*
Social and Environmental	19 (76)	6 (24)	2.53 (0.7)	1 – 4
Behavioural	15 (60)	10 (40)	2.93 (0.7)	2 – 4
Education and Employment	13 (52)	12 (48)	2.38 (1.2)	1 – 4
Biomarkers	7 (28)	18 (72)	1.71 (1.0)	1 – 3
Physical Health	9 (36)	16 (64)	2.67 (1.0)	1 – 4
Psychological and Mental Health	17 (68)	8 (32)	3.00 (0.7)	2 – 4
Patterns of Service Use	9 (36)	16 (64)	2.56 (0.5)	2 – 3
Factors Identified to be Particularly Relevant to Under-Served Populations	7 (28)	18 (72)	2.14 (1.2)	0 – 4

* Expertise was self-rated on a scale of 0 – 4 where: 0 = None; 1 = Basic; 2 = Intermediate; 3 = Advanced; 4 = Expert.

The full results of the risk factor ranking exercise are presented in Appendix A.1 (Table 45 to Table 51 for the main framework; domains 1-7, and Table 52 for the domain relating to under-served populations; domain 8). The top five ranked risk factors per domain are summarised overleaf in Figure 8.

Appendix A.2 (Table 53) presents the risk factors which no respondents felt able to rate. There were a total of 15 unrated risk factors, from two domains. The majority (n=14) of unrated risk factors were from the ‘Biomarkers’ domain; the only other unrated factor (n=1) was from the ‘Physical Health’ domain.

Figure 8: Top five ranked risk factors in each domain

 Domain 1: Social and Environmental	
Position (of 106)	Risk Factor
1 st	Being a looked after child (LAC)
2 nd	Torture
3 rd	Sexual abuse
4 th	Lack of supportive relationship(s) with a trusted adult
Tied 5 th	Poor primary caregiver-caregiver relationship
	Cumulative traumatic events

 Domain 2: Behavioural	
Position (of 23)	Risk Factor
1 st	Heavy alcohol use
2 nd	Poor sleep patterns
3 rd	Sexual risk-taking
4 th	Prescription drug abuse
5 th	Higher behavioural inhibition

 Domain 3: Education and Employment	
Position (of 25)	Risk Factor
1 st	School exclusions
2 nd	Quality of school climate (e.g. relating to school connectedness, feelings of safety in school, perception of school, adult-student relationships, morale)
Tied 3 rd	Disruptive behaviours in school (e.g. defiance and non-compliance)
	Poor peer relationships
	Poor school attendance
	Poor teacher-pupil relationship

 Domain 4: Biomarkers	
Position (of 48)	Risk Factor
1 st	Low intelligence quotient (IQ)
2 nd	Genetic markers
3 rd	Sex (biological)
4 th	Nutritional deficits
5 th	Neurotoxicity

 Domain 5: Physical Health	
Position (of 52)	Risk Factor
1 st	Traumatic brain injury
2 nd	Primary caregiver(s) chronic (long lasting) illness
3 rd	Severe health condition
4 th	Severe illness in family
5 th	Sleep disorder

 Domain 6: Psychological and Mental Health	
Position (of 26)	Risk Factor
1 st	Family history of severe mental illness (e.g. psychosis)
2 nd	Primary caregiver(s) mental health problems
3 rd	Psychiatric history
4 th	Family history of psychiatric disorders
5 th	Social-communication problems

 Domain 7: Patterns of Service Use	
Position (of 7)	Risk Factor
1 st	Child protection register
2 nd	Investigations by multiple services suggestive of suffering from medically unexplained symptoms
3 rd	Failure to attend three or more planned health or social care appointments
4 th	Three or more presentations to emergency services within a year
5 th	Repeat hospitalisation

 Domain 8: Under-Served Populations	
Position (of 102)	Risk Factor
1 st	Being a looked after child (LAC)
2 nd	Child in need (CIN) status
3 rd	Torture
4 th	Separation from family (e.g. out-of-home care)
5 th	Child protection record

4.5.1.7.1 Summary of findings: overall changes to the framework

Table 14 provides a summary of the main changes to the framework of risk factors over all rounds of the Delphi survey. The final theoretical framework can be found in Figure 32 (Appendix A.4). Based on respondents' feedback, the framework changed significantly, with new life course stages and domain groupings, an altered approach to mitigating health inequalities, and new risk factors added. The feedback also led to domain rankings and risk factor rankings to inform prioritisation of factor extraction using NLP methods, and to heat maps illustrating the importance of exposure to each risk factor at different stages of a young person's life.

Table 14: Summary of the main changes to the framework over all three rounds

Type of change	Description of change
Ecological Levels	Added levels ('individual-', 'family/caregiver-', and 'society-level') to the domains, indicating via which channel risk factors act upon an individual young person
Domain Groupings	Refined the domains and their names
Life Course Groupings	Refined the life course stage groupings by making them more granular
Mitigating Health Inequalities	Added a domain specifically for those from under-served groups, taking risk factors from the other seven domains to highlight factors particularly salient to these populations; this resulted in 102 risk factors salient to under-served populations
Changes to Risk Factors	Added missing risk factors (from the original 193 to 287 risk factors following the Delphi consultation). Also combined and renamed risk factors where appropriate
Risk Factor Ranking	Ranked the risk factors within domains in order of importance for predicting mental health problems
Life Course Stages	Created heat maps to indicate where in the life course exposure to each risk factor is particularly salient for the development of mental health problems

4.5.2 Results – Part 2: ACEs only

From the main framework (domains 1-7), a total of 51 of the 287 risk factors (i.e. 17.8%) were classified as ACEs by the definitions of this thesis; this consisted of 7 at the society-level, 18 at the family/caregiver-level, and 26 at the individual-level (including factors experienced in utero). From the under-served domain (domain 8),⁴ there were a total of 35 out of the 102 risk factors (i.e. 34.3%) classified as ACEs; these consisted of 7 at the society-level, 10 at the family/caregiver-level, and 18 at the individual-level (including factors experienced in utero).

Of the eight possible domains, risk factors which would be classified as ACEs fell into a total of four of the domains.

⁴ As a reminder, this final domain, domain 8, contained repeats of risk factors from the other seven domains if they related to under-served populations, whereas the other seven domains contained unique risk factors only.

These were domains:

- 1: 'Social and Environmental', containing 45 ACEs;
- 6: 'Psychological and Mental Health', containing 5 ACEs;
- 7: 'Patterns of Service Use', containing 1 ACE;
- 8: 'Factors Identified to be Particularly Relevant to Under-Served Populations', containing 35 ACEs.

4.5.2.1 Findings: life course stages of greatest salience (Rounds 2 and 3)

Life course stages of greatest salience for mental health problem development are shown in heat maps in the following section (Figure 9 and Figure 10). These are broken down into ACEs from the main framework (domains 1-7) and ACEs relating to under-served populations (domain 8). The proportions underlying the heat maps are also shown in numerical form in Table 15 and Table 16, respectively.

Of note, when analysis was carried out it appeared that by giving respondents a time-saving option to tick 'all life course stages' (instead of manually checking individual stages), this may have led to some logically impossible results. Alternatively, some respondents may have misunderstood certain risk factors. In some parts of the heat maps (and corresponding tables), a life course stage is indicated as somewhat important yet the factor could not possibly be experienced at that life stage. For example, the life course stage pregnancy showing as important when a factor must occur post-birth (like 'torture' or 'victim of bullying'). In the interest of completeness, and to avoid subjective post-hoc amendments to the results, all collected data are shown in the heat maps and tables. However, this potential artefact should be borne in mind if a response appears logically impossible.

4.5.2.1.1 ACEs within domains 1-7

As can be seen in Figure 9 and Table 15, most of the ACEs within the main framework (domains 1-7) were rated as highly important if experienced at any life course stage, with darker shades in the figure indicating more importance at that stage. The number of respondents ranged from 11 to 32 for risk factors identified as ACEs, with the median number of respondents being 28 and the interquartile range (IQR) being 14 to 30. The average number of respondents for ACEs was relatively high (compared to all risk factors within the Delphi domains), though there was a reasonable range depending on which specific ACE was being rated.

4.5.2.1.2 ACEs within domain 8

As can be seen in Figure 10 and Table 16, there was relatively minimal variation in the proportion of importance ascribed at each life course stage. In general, respondents commenting on ACEs experienced by those from under-served groups indicated that exposure to ACEs was fairly equally important across each part of the life course, and irrespective of ACE type. They rated the importance as high, with many ACEs having a proportion rating of 1.0 (i.e. the maximum possible).

The number of respondents ranged from 5 to 14 for risk factors in domain 8 identified as ACEs, with the median number of respondents being 6 and the interquartile range (IQR) being 6 to 6. The low median highlights the small number of raters this domain generally had and the IQR highlights the small spread in number of raters for ACEs within this domain.

Figure 9: Heat map to illustrate where in the life course exposure to ACEs is particularly harmful for the mental health outcomes of young people (domains 1-7)



Table 15: Proportion of importance by life course stage for ACEs from domains 1-7

Level	Risk factor	Domain	Life course stage					Number of raters (N)
			Pregnancy	Birth-2 years	3-11 years	12-17 years	18-25 years	
Society	Cultural racism	S & E	0.93	0.93	1.00	1.00	1.00	14
	Gangland crime	S & E	0.50	0.54	0.75	1.00	0.96	28
	Living in an area with high crime levels	S & E	1.00	0.77	0.92	1.00	0.69	13
	Racial bias in obstetric care	S & E	1.00	0.75	0.58	0.42	0.42	12
	Radicalisation	S & E	0.38	0.38	0.54	1.00	1.00	13
	Victim of structural/systemic racism	S & E	0.92	0.92	1.00	1.00	1.00	13
	War/conflict	S & E	1.00	1.00	1.00	1.00	1.00	28
Family/Caregiver	Being an asylum-seeking family	S & E	1.00	1.00	1.00	1.00	1.00	14
	Blended or complex family structure	S & E	0.83	1.00	1.00	1.00	0.92	12
	Death of primary caregiver(s)	S & E	0.83	1.00	1.00	1.00	0.80	30
	Domestic violence	S & E	1.00	0.97	0.97	1.00	0.90	30
	Family conflict or discord	S & E	0.97	1.00	1.00	1.00	0.87	30
	Family experience of social exclusion, discrimination and harassment associated with ethnicity	S & E	0.90	0.97	1.00	1.00	1.00	30
	Family history of psychiatric disorders	P & MH	0.88	0.88	0.91	0.91	0.91	31
	Family history of severe mental illness (e.g. psychosis)	P & MH	0.88	0.88	0.91	0.91	0.91	32
	Homelessness	S & E	1.00	1.00	1.00	1.00	1.00	14
	Household alcohol abuse	S & E	1.00	1.00	1.00	0.97	0.87	30
	Household criminality	S & E	0.86	0.90	0.97	1.00	0.93	29
	Household drug abuse	S & E	1.00	0.97	1.00	0.97	0.87	30
	Household member involvement in criminal justice system	S & E	0.85	0.85	0.92	1.00	1.00	13
	Household mental illness	S & E	1.00	1.00	1.00	1.00	0.97	30
	Imprisonment of household member	S & E	0.92	0.92	1.00	1.00	0.92	13
	Primary caregiver(s) marital status	S & E	0.73	0.73	0.73	0.73	0.73	11
	Primary caregiver(s) mental health problems	P & MH	0.91	0.88	0.91	0.91	0.79	32

Individual	Single parent/caregiver family	S & E	0.84	0.92	0.88	0.80	0.60	23
	Being a looked after child (LAC)	S & E	0.79	1.00	1.00	1.00	0.86	14
	Being a young carer	S & E	0.39	0.39	0.89	0.89	0.79	26
	Being an unaccompanied asylum seeker	S & E	0.71	0.86	0.79	0.93	0.93	14
	Child in need (CIN) status	S & E	0.64	0.93	1.00	1.00	0.64	14
	Child protection record	PSU	0.79	0.86	0.93	0.86	0.86	13
	Emotional neglect	S & E	0.80	1.00	1.00	0.97	0.83	30
	Emotional, psychological or verbal abuse	S & E	0.77	1.00	1.00	1.00	0.90	30
	Experience of racism and discrimination	S & E	0.67	0.67	0.97	0.97	0.93	29
	Experiencing financial abuse	S & E	0.82	0.73	0.73	0.73	1.00	11
	Frequent fear of family member	S & E	0.72	0.93	0.97	0.97	0.90	28
	Homelessness (young person has left home)	S & E	0.36	0.29	0.57	0.86	1.00	14
	Maternal alcohol use during pregnancy	S & E	0.97	0.83	0.76	0.76	0.72	28
	Maternal depression during pregnancy	P & MH	0.84	0.77	0.65	0.61	0.58	29
	Maternal psychosis (perinatal or pre-natal)	P & MH	0.84	0.84	0.66	0.63	0.56	30
	Maternal substance abuse during pregnancy	S & E	0.97	0.83	0.77	0.77	0.73	29
	Maternal use of psychotropics during pregnancy	S & E	0.97	0.79	0.66	0.62	0.62	28
	Organised crime affiliation	S & E	0.62	0.62	1.00	1.00	1.00	13
	Physical abuse	S & E	0.87	0.97	1.00	0.97	0.90	30
	Physical neglect	S & E	0.83	0.97	1.00	0.93	0.83	30
	Separation from family (e.g. out-of-home care)	S & E	0.67	0.97	1.00	1.00	0.80	30
	Sexual abuse	S & E	0.80	0.97	1.00	1.00	0.97	30
	Torture	S & E	0.90	0.97	0.97	1.00	1.00	30
	Victim of bullying	S & E	0.50	0.53	1.00	1.00	0.87	30
	Victim of organised crime (e.g. commercial sexual exploitation or via county lines)	S & E	0.62	0.62	0.85	1.00	1.00	13
	Victim or witness of violent crime	S & E	0.79	0.83	1.00	1.00	0.93	29
	Witness of community violence	S & E	0.67	0.78	1.00	1.00	0.93	27
								Range:
								11 - 32

S & E = Social and Environmental; P & MH = Psychological and Mental Health; PSU = Patterns of Service Use

Figure 10: Heat map to illustrate where in the life course exposure to ACEs is particularly harmful for the mental health outcomes of young people from under-served populations (domain 8)



Credit: created with flourish.studio (<https://flourish.studio>).

Table 16: Proportion of importance by life course stage for ACEs from domain 8 (i.e. relating to under-served populations)

Level	Risk factor	Domain	Life course stage					Number of raters (N)
			Pregnancy	Birth-2 years	3-11 years	12-17 years	18-25 years	
Society	Cultural racism	U-S	0.67	0.67	0.83	1.00	1.00	6
	Gangland crime	U-S	0.47	0.47	0.67	0.93	0.93	14
	Living in an area with high crime levels	U-S	0.83	0.83	0.83	1.00	1.00	6
	Racial bias in obstetric care	U-S	1.00	0.60	0.20	0.20	0.20	5
	Radicalisation	U-S	0.83	0.83	0.83	1.00	0.83	6
	Victim of structural/systemic racism	U-S	0.83	0.83	1.00	1.00	1.00	6
	War/conflict	U-S	0.92	0.92	0.92	0.92	0.92	12
Family/Caregiver	Being an asylum-seeking family	U-S	1.00	1.00	1.00	1.00	1.00	6
	Family experience of social exclusion, discrimination and harassment associated with ethnicity	U-S	0.73	0.73	0.87	0.87	0.80	13
	Homelessness	U-S	1.00	1.00	1.00	1.00	1.00	6
	Household alcohol abuse	U-S	1.00	1.00	1.00	1.00	1.00	6
	Household criminality	U-S	1.00	1.00	1.00	1.00	1.00	6
	Household drug abuse	U-S	1.00	1.00	1.00	1.00	1.00	6
	Household member involvement in criminal justice system	U-S	1.00	1.00	1.00	1.00	1.00	6
	Household mental illness	U-S	1.00	1.00	1.00	1.00	1.00	6
	Imprisonment of household member	U-S	1.00	1.00	1.00	1.00	1.00	5
	Primary caregiver(s) mental health problems	U-S	1.00	1.00	1.00	1.00	1.00	6
Individual	Being a looked after child (LAC)	U-S	1.00	1.00	1.00	1.00	1.00	6
	Being a young carer	U-S	0.43	0.43	0.93	0.86	0.64	13
	Being an unaccompanied asylum seeker	U-S	0.83	1.00	1.00	1.00	0.83	6
	Child in need (CIN) status	U-S	0.83	1.00	1.00	1.00	0.83	6
	Child protection record	U-S	1.00	1.00	1.00	1.00	1.00	6
	Experience of racism and discrimination	U-S	0.57	0.57	0.86	0.86	0.86	13
	Homelessness (young person has left home)	U-S	0.50	0.50	0.83	1.00	1.00	6

Maternal alcohol use during pregnancy	U-S	1.00	1.00	1.00	0.83	0.83	6
Maternal depression during pregnancy	U-S	1.00	1.00	1.00	0.80	0.80	5
Maternal psychosis (perinatal or pre-natal)	U-S	1.00	1.00	0.80	0.80	0.80	5
Maternal substance abuse during pregnancy	U-S	1.00	1.00	1.00	0.83	0.83	6
Maternal use of psychotropics during pregnancy	U-S	1.00	1.00	1.00	0.83	0.83	6
Organised crime affiliation	U-S	0.33	0.33	0.67	0.83	1.00	6
Separation from family (e.g. out-of-home care)	U-S	0.83	1.00	1.00	1.00	1.00	6
Torture	U-S	1.00	1.00	1.00	1.00	1.00	6
Victim of organised crime (e.g. commercial sexual exploitation or via county lines)	U-S	0.67	0.67	0.83	0.83	1.00	6
Victim or witness of violent crime	U-S	0.67	0.83	1.00	1.00	1.00	6
Witness of community violence	U-S	0.80	0.80	1.00	1.00	1.00	5

Range:
5 - 14

U-S = Factors Identified to be Particularly Relevant to Under-Served Populations

4.5.2.2 Findings: ranking of ACEs (Round 3)

All risk factors within the Delphi received a rank within their domain, as described in previous sections. The following results show how risk factors classified as ACEs ranked within each domain, among non-ACE risk factors.

Figure 11 summarises how highly ranked ACEs were among the top five ranked risk factors (within the four domains in which ACEs featured). As shown, ACEs were ranked in many of the top positions for each of the domains in which they featured. The top three positions in domain 1 were ACEs. However, the lowest ranked risk factor in this domain (placed at position 106) was also an ACE – ‘Primary caregiver(s) marital status’ – a proxy indicator for parental separation or divorce. The top two positions in domain 6 were ACEs, and the only ACE to feature in domain 7 was ranked in the top position. Finally, the top five positions in domain 8, relating to under-served populations, were ACEs. Even the lowest ranked ACE within this domain – ‘Living in an area with high crime levels’ – still placed at position 70 of 102.

Figure 11: Position of ACEs among top five ranked risk factors within domains

 Domain 1: Social and Environmental		 Domain 6: Psychological and Mental Health	
Position (of 106)	Risk Factor	Position (of 26)	Risk Factor
1 st	Being a looked after child (LAC)	1 st	Family history of severe mental illness (e.g. psychosis)
2 nd	Torture	2 nd	Primary caregiver(s) mental health problems
3 rd	Sexual abuse	3 rd	[Not an ACE]
4 th	[Not an ACE]	4 th	[Not an ACE]
Tied 5 th	[Not ACEs]	5 th	[Not an ACE]

 Domain 7: Patterns of Service Use		 Domain 8: Under-Served Populations	
Position (of 7)	Risk Factor	Position (of 102)	Risk Factor
1 st	Child protection register	1 st	Being a looked after child (LAC)
2 nd	[Not an ACE]	2 nd	Child in need (CIN) status
3 rd	[Not an ACE]	3 rd	Torture
4 th	[Not an ACE]	4 th	Separation from family (e.g. out-of-home care)
5 th	[Not an ACE]	5 th	Child protection record

Table 17 and Table 18 present the full ACE ranking results (from the main framework and from the under-served domain, respectively). The tables provide the ranked position of each ACE within each domain, along with a mean score (used to rank the factors), confidence intervals, and number of raters per ACE. In contrast to the non-ACEs described in Results – Part 1 (see Page 36 onwards), each ACE had at least one respondent able to comment on it, thus none of the ACEs were unable to be ranked.

Table 17: Ranked importance of ACEs within domains; results for domains 1-7

Tied position	Rank of ACE among all risk factors	Number of risk factors in domain	Risk factor	Number of raters (N)	Mean score	Lower bound (CI)	Upper bound (CI)	Domain	Level
	1	of 106	Being a looked after child (LAC)	14	0.014	0.010	0.025	S & E	Ind
	2	of 106	Torture	13	0.014	0.003	0.024	S & E	Ind
	3	of 106	Sexual abuse	16	0.014	0.012	0.023	S & E	Ind
=	7	of 106	Domestic violence	16	0.013	0.011	0.023	S & E	F/C
	9	of 106	Emotional, psychological or verbal abuse	16	0.013	0.012	0.024	S & E	Ind
	10	of 106	Emotional neglect	16	0.013	0.011	0.025	S & E	Ind
	11	of 106	Victim of organised crime (e.g. commercial sexual exploitation or via county lines)	13	0.013	0.011	0.022	S & E	Ind
=	12	of 106	Household drug abuse	16	0.013	0.010	0.021	S & E	F/C
	14	of 106	Physical abuse	16	0.013	0.008	0.020	S & E	Ind
	15	of 106	Household mental illness	16	0.013	0.010	0.020	S & E	F/C
	16	of 106	Family conflict or discord	16	0.013	0.009	0.023	S & E	F/C
	17	of 106	Death of primary caregiver(s)	16	0.013	0.009	0.020	S & E	F/C
	19	of 106	Separation from family (e.g. out-of-home care)	15	0.012	0.011	0.022	S & E	Ind
=	20	of 106	Homelessness	16	0.012	0.008	0.023	S & E	F/C
	22	of 106	Household alcohol abuse	16	0.012	0.009	0.021	S & E	F/C
	23	of 106	Family experience of social exclusion, discrimination and harassment associated with ethnicity	14	0.012	0.008	0.022	S & E	F/C
	24	of 106	Victim or witness of violent crime	13	0.012	0.009	0.018	S & E	Ind
	26	of 106	Physical neglect	16	0.012	0.003	0.021	S & E	Ind
	28	of 106	Being an unaccompanied asylum seeker	15	0.012	0.005	0.021	S & E	Ind
=	29	of 106	Being an asylum-seeking family	14	0.012	0.008	0.017	S & E	F/C
=	29	of 106	Victim of bullying	16	0.012	0.009	0.015	S & E	Ind
=	31	of 106	Experience of racism and discrimination	15	0.012	0.007	0.017	S & E	Ind
=	31	of 106	Child in need (CIN) status	15	0.012	0.003	0.021	S & E	Ind
	33	of 106	Maternal substance abuse during pregnancy	14	0.012	0.005	0.019	S & E	Ind

	36	of 106	Frequent fear of family member	16	0.012	0.004	0.022	S & E	Ind
=	37	of 106	Homelessness (young person has left home)	15	0.012	0.009	0.018	S & E	Ind
	39	of 106	War/conflict	13	0.012	0.007	0.026	S & E	Soc
	40	of 106	Victim of structural/systemic racism	13	0.012	0.002	0.017	S & E	Soc
	41	of 106	Witness of community violence	13	0.012	0.008	0.016	S & E	Ind
	42	of 106	Household criminality	16	0.012	0.006	0.017	S & E	F/C
	45	of 106	Household member involvement in criminal justice system	16	0.011	0.006	0.018	S & E	F/C
	48	of 106	Maternal use of psychotropics during pregnancy	11	0.011	0.002	0.019	S & E	Ind
	49	of 106	Imprisonment of household member	14	0.011	0.002	0.015	S & E	F/C
	50	of 106	Maternal alcohol use during pregnancy	15	0.011	0.005	0.019	S & E	Ind
	52	of 106	Cultural racism	14	0.011	0.005	0.026	S & E	Soc
	53	of 106	Organised crime affiliation	12	0.011	0.007	0.013	S & E	Ind
	61	of 106	Gangland crime	13	0.011	0.003	0.016	S & E	Soc
	62	of 106	Being a young carer	16	0.011	0.006	0.019	S & E	Ind
=	64	of 106	Experiencing financial abuse	13	0.010	0.004	0.014	S & E	Ind
	76	of 106	Radicalisation	12	0.010	0.001	0.019	S & E	Soc
	78	of 106	Racial bias in obstetric care	11	0.009	0.001	0.018	S & E	Soc
	82	of 106	Living in an area with high crime levels	13	0.009	0.001	0.013	S & E	Soc
	89	of 106	Blended or complex family structure	16	0.007	0.003	0.019	S & E	F/C
	101	of 106	Single parent/caregiver family	16	0.005	0.000	0.011	S & E	F/C
	106	of 106	Primary caregiver(s) marital status	16	0.003	0.000	0.009	S & E	F/C
				Range: 11 - 16					
	–	of 23	–	–	–	–	–	Beh	–
				Range: N/A					
	–	of 25	–	–	–	–	–	E & E	–
				Range: N/A					
	–	of 48	–	–	–	–	–	Bio	–

			Range: N/A					
–	of 52	–	–	–	–	–	PH	–
			Range: N/A					
1	of 26	Family history of severe mental illness (e.g. psychosis)	14	0.050	0.034	0.071	P & MH	F/C
2	of 26	Primary caregiver(s) mental health problems	14	0.046	0.038	0.072	P & MH	F/C
4	of 26	Family history of psychiatric disorders	14	0.043	0.034	0.074	P & MH	F/C
11	of 26	Maternal psychosis (perinatal or pre-natal)	12	0.040	0.023	0.054	P & MH	Ind
22	of 26	Maternal depression during pregnancy	12	0.038	0.012	0.044	P & MH	Ind
			Range: 12 - 14					
1	of 7	Child protection record	6	0.203	0.158	0.273	PSU	Ind
			Range: 6 - 6					

Headers: **CI** = confidence intervals

Domain: **S & E** = Social and Environmental; **Beh** = Behavioural; **E & E** = Education and Employment; **Bio** = Biomarkers; **PH** = Physical Health; **P & MH** = Psychological and Mental Health; **PSU** = Patterns of Service Use
 = = tied ranking

Level: **Soc** = Society-level; **F/C** = Family/caregiver-level; **Ind** = Individual-level

Table 18: Ranked importance of ACEs within domain; results for domain 8 (i.e. relating to under-served populations)

Tied position	Rank of ACE among all risk factors	Number of risk factors in domain	Risk factor	Number of raters (N)	Mean score	Lower bound (CI)	Upper bound (CI)	Domain	Level
	1	of 102	Being a looked after child (LAC)	5	0.016	0.011	0.029	U-S	Ind
	2	of 102	Child in need (CIN) status	5	0.016	0.011	0.021	U-S	Ind
	3	of 102	Torture	5	0.015	0.012	0.019	U-S	Ind
	4	of 102	Separation from family (e.g. out-of-home care)	6	0.015	0.012	0.027	U-S	Ind
	5	of 102	Child protection record	6	0.015	0.012	0.022	U-S	Ind
	7	of 102	Victim of organised crime (e.g. commercial sexual exploitation or via county lines)	5	0.014	0.012	0.021	U-S	Ind
	9	of 102	Homelessness (young person has left home)	6	0.014	0.012	0.025	U-S	Ind
	10	of 102	Primary caregiver(s) mental health problems	6	0.014	0.011	0.028	U-S	F/C
	11	of 102	Victim or witness of violent crime	6	0.013	0.007	0.016	U-S	Ind
	13	of 102	Victim of structural/systemic racism	6	0.013	0.003	0.017	U-S	Soc
	14	of 102	Being an asylum-seeking family	6	0.013	0.009	0.018	U-S	F/C
	15	of 102	Homelessness	6	0.013	0.011	0.018	U-S	F/C
	16	of 102	Household mental illness	6	0.013	0.012	0.023	U-S	F/C
	17	of 102	War/conflict	6	0.013	0.011	0.016	U-S	Soc
=	18	of 102	Gangland crime	6	0.013	0.004	0.016	U-S	Soc
=	18	of 102	Family experience of social exclusion, discrimination and harassment associated with ethnicity	6	0.013	0.003	0.017	U-S	F/C
	22	of 102	Experience of racism and discrimination	6	0.013	0.009	0.020	U-S	Ind
	25	of 102	Being an unaccompanied asylum seeker	6	0.012	0.012	0.021	U-S	Ind
=	27	of 102	Household drug abuse	6	0.012	0.011	0.016	U-S	F/C
=	27	of 102	Household member involvement in criminal justice system	6	0.012	0.012	0.013	U-S	F/C
	29	of 102	Being a young carer	6	0.012	0.005	0.017	U-S	Ind
	30	of 102	Radicalisation	6	0.012	0.002	0.016	U-S	Soc
	31	of 102	Organised crime affiliation	5	0.012	0.010	0.013	U-S	Ind

32	of 102	Household alcohol abuse	6	0.012	0.010	0.016	U-S	F/C
34	of 102	Witness of community violence	6	0.012	0.007	0.013	U-S	Ind
37	of 102	Household criminality	6	0.012	0.011	0.015	U-S	F/C
38	of 102	Imprisonment of household member	5	0.012	0.006	0.012	U-S	F/C
41	of 102	Maternal substance abuse during pregnancy	6	0.012	0.005	0.015	U-S	Ind
44	of 102	Cultural racism	6	0.011	0.003	0.018	U-S	Soc
48	of 102	Maternal use of psychotropics during pregnancy	5	0.011	0.004	0.016	U-S	Ind
49	of 102	Maternal alcohol use during pregnancy	6	0.011	0.003	0.015	U-S	Ind
= 56	of 102	Maternal depression during pregnancy	5	0.010	0.004	0.012	U-S	Ind
59	of 102	Maternal psychosis (perinatal or pre-natal)	5	0.010	0.006	0.015	U-S	Ind
67	of 102	Racial bias in obstetric care	5	0.010	0.001	0.014	U-S	Soc
70	of 102	Living in an area with high crime levels	6	0.009	0.001	0.013	U-S	Soc

Range:

5 - 6

Headers: **CI** = confidence intervals

Domain: **U-S** = Factors Identified to be Particularly Relevant to Under-Served Populations

= = tied ranking

Level: **Soc** = Society-level; **F/C** = Family/caregiver-level; **Ind** = Individual-level

4.6 Discussion

4.6.1 What was found

Through this literature review and Delphi process, we were able to iteratively refine a framework of risk factors for inclusion into early identification models, taking account of diverse opinions from experts in a broad range of fields relating to childhood mental health problems. This included academics, clinicians and professionals, such as psychiatrists, psychologists, teachers, social workers, and public health professionals, among others. The process of a literature search and discussion with professionals to create an initial prototype theoretical framework of risk factors, followed by the gradual refinement of the framework through incorporation of different expert opinions, should have added a level of rigour and robustness to the creation of the final framework. Furthermore, this process aligned with several recommendations for minimising model bias, highlighted by a systematic review of over two decades of research on clinical prediction models in psychiatry (Meehan et al., 2022). Specifically, these recommendations were to select candidate predictors a priori and base this selection on existing research evidence, clinical experience or previous models; such measures improve the likelihood of developing prediction models fit for clinical use. In addition, we made intentional and concerted efforts to consider health inequalities at each step of the process, building mitigations into the framework in order to reduce these biases, i.e. through the inclusion of a specific domain on under-served populations and the addition of new salient risk factors. We also hoped to consult with respondents from diverse ethnic backgrounds to bring their insights into the framework. Despite purposive sampling, these efforts were only somewhat successful, as demonstrated by the demographic makeup of the respondent sample (see Table 2). By explicitly trying to address health inequalities in the development of this framework, we believe it will go some way to mitigate health inequalities in subsequent algorithm development. However, other safeguards would also need to be put in place, recognising that algorithms are only as good as the data on which they are developed, which have historically inbuilt biases against certain populations (Knight et al., 2021). These safeguards should involve, but not be limited to, consideration for the principles of responsible artificial intelligence (AI). These principles include transparency, consideration of biases, inclusion, data privacy, and maintenance of ethical standards (Warrier, Warrier, & Khandelwal, 2023; World Health Organization, 2021).

Other useful changes based on the panel's feedback included the alteration of domain groupings and the increased granularity of life course stages. Later, the life course stage data could perhaps be used to develop risk prediction models for certain age groups, or to prioritise inclusion of risk factors from given timepoints in a child's life, such as prioritisation of early- to mid-life risk factors. This would be

in line with many key historic findings about the developmental importance of early life (see for example, Ainsworth, 1978; G. Allen, 2011; Bowlby, 1969; Gopnik, Meltzoff, & Kuhl, 1999; Heckman, 2012; Marmot, 2012).

Further, the domain groupings and rankings gave some small indication of what sorts of data sources may be helpful to access and incorporate into risk modelling development. With the 'Social and Environmental' domain ranked as most important for predicting mental health problems, 'Psychological and Mental Health' placing second, and 'Behavioural', 'Biomarkers' and 'Education and Employment' tying for fourth position, this could be understood as support for the legitimacy of bringing together data from a variety of sources, not just health data, if the aim is to predict childhood mental health problems earlier. For example, to accurately identify emerging mental health problems earlier, it may be important to understand a child's environment (e.g. through local authority and council data), their educational experience (e.g. through school data), their social experience (e.g. through linkage of household data) and their psychological experience (e.g. through child-reported measures, survey data or interview data). Of course, the rankings could also be a function of the interests of the experts in our Delphi panel; we tried to mitigate against this bias by including respondents from diverse fields, as well as by testing whether certain domains would be more likely to be ranked if they closely aligned with commonly occurring fields of expertise. These safeguards should have helped but bias in domain rankings remains a possibility. Nevertheless, helpful insights can be taken from these rankings, such as the fact that 'Biomarkers' were ranked relatively highly yet are rarely collected in routine care of children. The fact these data are not routinely-collected makes it difficult to translate a prediction tool reliant on genomic factors into the clinic, as the data are not available. In the future, however, this may change as there is a move towards collection and inclusion of more biomarker data, such as that of the NIHR D-CYPHR project (NIHR BioResource, 2025) and the Generation Study (Genomics England, 2024).

Another useful addition based on respondents' feedback was that of the levels of risk factors, inspired by Bronfenbrenner's ecological systems theory of development (later revised as the bioecological model; Bronfenbrenner, 1979; Bronfenbrenner & Morris, 2006), recognising the interconnectedness of levels, and explicitly positioning the child's development within a contributing system rather than in isolation. This recommendation was useful as it aligned the final framework of risk factors more closely with a widely-accepted framework already in use in the field of child development (Bronfenbrenner's ecological model). In addition, the suggestion to include levels also provided insight into the types of data that might be useful for risk prediction models. Specifically, risk prediction

models would ideally include not only a child's data, but also data from their family or caregivers, as well as data about their wider context. Interestingly, similar conceptual frameworks have been independently created for related populations, suggesting this may be an acceptable approach to the problem of meaningfully organising risk factors for mental health problems. For example, there is a conceptual framework of determinants of public mental health (Dykxhoorn et al., 2022) and a framework for depression in young people (Thapar, Eyre, Patel, & Brent, 2022), both of which incorporate different levels and/or systems like the final Delphi framework.

With regard to ACEs specifically, the life course heat maps provided interesting suggestions about when exposure to ACEs may be especially impactful on mental health outcomes. This is caveated by the limitation that this was based on responses from a relatively small and select group of individuals, so is by no means definitive. The Delphi process also revealed how highly many of these factors ranked in the risk factor ranking exercise, supporting my hypothesis that it is important to include ACEs when trying to predict mental health problems earlier. Furthermore, it supported the idea that ACEs may be a good target for intervention if we are to develop a preventative approach to mental health problems. However, not all ACEs ranked highly, in particular those relating to family composition (i.e. parental separation or divorce). This is in part reflective of the broad spectrum that makes up 'ACEs', compared to 'traumas'. It could be argued that it is now outdated to include parental separation or divorce as ACEs, based on old-fashioned ideas about nuclear families. However, parental separation or divorce are often still included in academic literature, and more importantly are still cited by some young people as an adversity (R. Meiser-Stedman, personal communications, circa 2018), perhaps supporting inclusion in the present framework. It may be that the context surrounding divorce or separation, such as parental conflict, financial worries, housing stressors, and changes to family structures (e.g. new stepparents and stepsiblings) is adverse for some, but by no means all, young people (Cox & Paley, 2003; Harold & Sellers, 2018), and this may differ across cultures and eras given changing stigma. Many young people, in contrast, experience parental separation or divorce as protective, positive or neutral. As with many of the included 'risk factors' in this framework, context matters. Given that the Delphi framework seeks to include predictors (or correlated factors), not causal factors, of mental health problems, it seems justified to retain this ACE in my definition, whilst acknowledging its low rank of importance compared to more extreme ACEs such as abuses, neglect, and social care involvement. Moreover, the Delphi framework itself is an entirely untested hypothesis developed via consensus of opinion, albeit expert but still opinion-based. In future work, the Timely team will test the actual associations between the risk factors and mental health outcomes, to determine how predictive they are.

Many of the ACEs, and in fact all the risk factors more generally, were ranked as highly important within domains, and also highly important across the life course, making differences difficult to disentangle, with many factors reaching a ceiling. This seems reflective of the risk factors included in the framework, and indicates we included the right sort of factors. That is, we purposely chose risk factors from literature, clinical discussions, and respondent suggestions that were deemed important for mental health problem prediction, thus all factors should be rated highly if we were incorporating the right (i.e. most predictive) factors. Actual early identification tool development and prototyping will help to answer the question of whether these factors are predictive in reality, using real-world administrative data.

When it comes to the early identification of childhood mental health problems, the evidence strongly suggests that ACEs are an important part of the story, but not the whole story. Many other risk factors were identified during the Delphi process which do not fit into the definition of ACEs used in this thesis, for example, poverty, food insecurity, war and conflict, physical health problems, memory issues and so on, but they nevertheless represent other important potential predictors to test in an early identification model. As an aside, these findings could arguably provide justification for expanding the definition of ‘adverse childhood experiences’ in future as the study highlighted various adversities not captured in the present definition, which are common in many countries and of increasing concern in Western contexts (such as war and food insecurity). The Delphi study highlights the importance of ACEs as factors within a broader context of important factors in a child’s life, including factors relating to the child, their caregiving network, and the society in which they live, as well as factors both early and later in life. When we think about ACEs, we often focus on the individual- and close family-level, but this process helped to situate the child as part of a wider system, including societal factors and factors relating to organisations with which children come into contact, such as the education, employment, social care, and healthcare systems.

4.6.2 Strengths, limitations and challenges

This study had a number of strengths and limitations, as well as highlighting various challenges and learning points, as detailed below. Firstly, we managed to retain a large number of respondents throughout the duration of the Delphi study, and ended with a final sample size which was in keeping with that of other such studies (Campbell, Wood, Lindberg, & Berger, 2021; Cheong, Lang, Hemphill, & Johnston, 2016; Hart, Damiano, Chittleborough, Paxton, & Jorm, 2014; Sahle, Reavley, Morgan, et al., 2021), although it was smaller than some Delphi studies which managed to gain participation from

over 100 respondents, including both members of the public (with or without lived experience of a condition) and professionals (Howarth et al., 2019; Perry, Ford, O'Mahen, & Russell, 2021). Our sample did also contain a broad range of professional expertise, including both academics and practicing clinicians/professionals (and those who identified as both), as well as a high number of years in their professions. This suggests we were reaching 'experts', an important achievement for a study of this type. Unfortunately, we were more limited in representation from certain fields, such as general practice and genetics, despite purposive sampling efforts.

A further strength of this study was its attempt and partial success of supporting the mitigation of health inequalities. By building in this aim explicitly from the outset, we were able to purposefully examine literature for relevant risk factors, consult with our team which included colleagues from different ethnic minority backgrounds, ask clinicians and professionals in the set-up phase, explicitly state this aim in the survey introduction and incorporate this aim into questions. These measures went some way to mitigating the fact that published academic literature on risk factors for those from under-served populations will be patchy and biased, as will professionals' expertise. Knight and colleagues (2021) note that health inequalities and biases are baked into each stage of the data science pipeline; we attempted to address them at each stage too, in order to combat this, as recommended by Knight and colleagues. We were successful at altering the framework to be more reflective of those from under-served populations, including by adopting the NIHR INCLUDE definitions of under-served populations (NIHR, 2020), adding an explicit domain focused on under-served populations instead of embedding this within the whole framework, and adding other key risk factors recommended by respondents, resulting in the final inclusion of 102 factors within this domain. We were less successful at recruiting more participants from ethnically diverse backgrounds, despite purposively contacting experts from different backgrounds and asking current respondents to share the survey with colleagues who may increase diverse representation. At times, this felt like a challenging topic to raise in a sensitive and respectful way, but it also felt important to do so explicitly rather than euphemistically if we were to be successful in this important aim. Though the ethnic diversity of the sample was limited, we did have diversity of gender and seniority (measured through years in profession).

Regarding challenges, a number of difficulties arose during the survey. Firstly, survey participation was understandably low during academic holiday periods, for example, in the run up to Christmas and just after, and this was compounded by the survey being run in the midst of the COVID-19 pandemic when it was harder to get clinical and educational professionals' input. We mitigated against low

participation by running the survey online, extending the completion window, sending reminders and also reminding participants of the prize draw for completion. Secondly, analysis proved more complex than anticipated, and there were delays between rounds to complete analysis and produce feedback reports; this could have impacted retention rates, but also ensured the accuracy of analysis. Thirdly, moving from one survey-hosting platform to another, to accommodate the functionality we required, presented some challenges for analysis of respondents' information across rounds. Fourthly, some platform background functionality created unexpected issues. For example, the fact that Qualtrics XM automatically coded 'N/As' (which we had renamed as 'Unable to Respond') as blank cells in sliding scale questions, presented a further challenge as we were left with three different types of 'blanks' to disentangle. The three were: 'Unable to Respond'; intentionally not moving the slider from 0; and not responding to the question (e.g. never presented with that domain or not continuing with the questions). We had anticipated and mitigated against the latter two types of blank values, but had not anticipated the first type. I sought technical support from the Qualtrics team and we found a solution which involved cross-checking answers and manually transferring responses over; this fix worked but was laborious. These challenges, though surmountable, did severely extend the amount of time it took to complete the Delphi survey. Though this was helped by our analysis plan in Rounds 2 and 3, where I had piloted the types of analysis I would carry out on dummy data (of the same type), data cleaning was still more complex than in this pilot.

A future study would need to time data collection dates to avoid major university holidays and block out large amounts of analysis time after each survey closure date. I would also retain the pilot analysis steps but make these more proactive and thorough, for example having a mock-up skeleton of the Delphi reports (i.e. report wording but without results), so that the survey creation, specific question wording and structure was even more closely mapped to the desired survey outputs from the beginning. However, it would still be important to maintain some of the flexibility and responsiveness of the questions asked in the Delphi, as this iterative and reactive approach is part of what makes the Delphi methodology useful for this topic. For example, on the advice of our steering group, a group of professionals in psychiatry and psychology who gave advice on analysis (including Prof. Peter Fonagy and Prof. Tamsin Ford), we added the extra question about the importance of risk factors at different life course stages, making the most of the wealth of expertise in our Delphi panel. Though not planned from the beginning, the iterative nature of a Delphi study allows informed deviations like this, to enhance the final results and properly utilise the panel expertise.

4.7 Conclusions

This theoretical framework, developed and refined iteratively, provides a roadmap of the ideal risk factors to include in an early identification model if it is to accurately predict childhood mental health problems and informs the build of relevant clinical informatics research infrastructure that will support this. It could also in part help to inform prevention and early intervention approaches for young people's mental health problems by providing avenues for further enquiry. As noted by Essex and colleagues (2006):

“Exploratory studies that generate testable models of how risk factors for childhood mental health problems work together over time are critical for developing effective prevention and treatment strategies.”

The framework contains a mix of risk factors which are routinely-collected and those which are not, so it provides something to aim for, but with the knowledge that it is unlikely to be practically possible to include all these factors in model building at the present time. However, digital advances in technology, as well as things like large language models (LLMs) mean that the data and means to collect data might vary significantly in the near future. Fortunately, it is also unlikely to be necessary to include every single risk factor to have sufficient detection power for clinical utility, and the risk factor prioritisation exercise provides a strong place to start with variable inclusion using data available at the present time. It also highlights instances of risk factors which are considered very important by the group, but are either not collected, are patchily collected (e.g. for certain populations, or within certain databases), or require enhanced extraction efforts to include them, such as the development of natural language processing algorithms to scrutinise unstructured data. For those which are not collected in any form but are ranked as highly predictive, it may be that there should be increased efforts to measure these and in standardised ways. For example, many of the highly ranked risk factors within the ‘Social and Environmental’ domain were ACEs, yet these may seldom be measured in children other than those from extremely vulnerable populations, such as young people in the social care system.

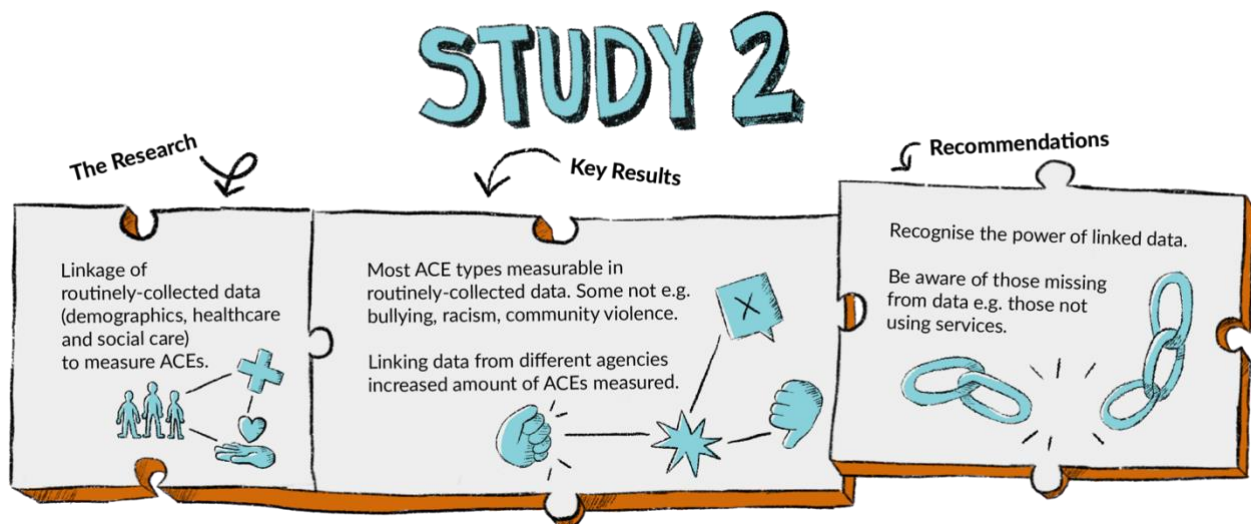
As described in Appendix A.6 (Section 9.1.6), I explored how many of these risk factors were theoretically possible to measure in routinely-collected data sources, and then in the next chapter (Chapter 5) I explored the extent to which it was actually possible to measure ACEs specifically, using various routinely-collected data sources.

This Delphi process essentially provided the Timely team with a risk factor ‘wish list’ of candidate variables for inclusion in models. In reality, any actual risk prediction models will be limited to the data available, and their predictive utility will vary accordingly, but this exercise provided a tangible and expert-informed starting point for model development. Furthermore, this framework provides a pathway for taking a transparent and interpretable approach, rather than a black-box approach to risk prediction. A black-box approach often lacks clinical utility and is generally less likely to be accepted or adopted by clinicians/professionals (Quinn, Jacobs, Senadeera, Le, & Coghlan, 2020; Rudin, 2019). Use of any machine learning or artificial intelligence approaches in mental healthcare must be carried out with principles of responsible AI in mind, including transparency, data privacy, consideration of biases, and inclusion (Warrier et al., 2023; World Health Organization, 2021). Based on the results of this Delphi, along with other literature referenced throughout this thesis, ACEs seem to form a valuable part of what should be included in a predictive tool if it is to be accurate (and thus, clinically useful) at mental health prediction in young people.

4.8 Supplementary analysis

In supplementary analysis (Appendix A.6), all 287 risk factors from domains 1-7 and 102 risk factors from domain 8 were mapped to variables in a databank of routinely-collected data. This work demonstrated the extent to which it might be possible to extract the Delphi framework risk factors from routinely-collected data and include in early identification models for young people’s mental health problems.

5 Chapter 5: Measurement of ACEs in a Database of Routinely-Collected, Linked Data



Credit: designed by Nifty Fox Creative, 2024.

5.1 Declaration of contributions

Some of the work within the Secure Anonymised Information Linkage (SAIL) Databank was carried out as part of a team (the Timely team, led by Dr Anna Moore) or involved collaborators (at the Adolescent Mental Health Data Platform (ADP), led by Prof. Ann John). Data access and data linkage was funded by What Works for Children's Social Care (WWCSC) and Cambridgeshire and Peterborough NHS Foundation Trust (CPFT), from grants to Dr Moore. Dr Yasmin Friedmann, a Senior Research Data Scientist at the ADP, linked the 18 databases together (work which was paid), forming a bedrock of all subsequent analysis. Prof. Ann John, Dr Marcos Del Pozo Baños, and Dr Hannah Evans kindly shared code lists they had developed and validated for measuring various mental health problems and child maltreatment, the latter of which facilitated a large part of the work in this chapter. Ad-hoc advice on using the maltreatment code lists was provided by Dr Del Pozo Baños, Dr Evans and Dr Amanda Marchant.

From the Timely team, Ryan Crowley carried out initial characterisation of the SAIL Databank as part of his Master's degree, including calculating the size of each of the 18 databases and exploring their temporal coverage. I then independently repeated this database characterisation exercise for the databases I used for final ACE measurement. Efthalia (Lina) Massou measured the prevalence of mental health problems within our cohort (described in the report Parkin et al., (2023)). Ryan and Lina both provided invaluable support in our initial exploration of SAIL together. Bianka Roku and Dr Rachel Sippy both provided advice on using diagnostic codes to identify cases, and creating event flags in SQL, respectively. Analysts and the technical support team from SAIL gave advice as and when required.

In terms of my work on this project, I independently carried out exploratory work to identify databases with similar characteristics to CADRE, describing the nature and costs of 16 different databases and identifying SAIL as the most appropriate option. I carried out the initial scoping process with SAIL, to identify if the databank was appropriate for our team's work, securing quotes and meeting with Dr Friedmann to discuss the project requirements. I supported Dr Moore in securing funding from WWCSC and, after securing funding, wrote update reports and presentations, and led on writing the technical report for WWCSC. I wrote the application to gain our team's access to SAIL, and liaised with the Information Governance Review Panel (IGRP). I worked closely with Dr Friedmann as she linked the databases and provided guidance on how the team wanted the data curated. I characterised the 18 databases using the SAIL metadata, writing descriptions of each database and mapping our variables of interest to the SAIL data dictionaries (whilst Ryan characterised the quality of the data within the databases). For the measurement of ACEs, I developed my own code lists to use alongside

the code lists shared by the ADP, carried out all measurement of ACEs independently and created visualisations for these.

Some of the content in this chapter is taken from a peer-reviewed published technical report, including parts of the Introduction, Methods, and Discussion sections, as well as a small portion of the Results:

Parkin, K., Crowley, R., Massou, E., Del Pozo Baños, M., Friedmann, Y., John, A., & Moore, A. (2023). *Towards Early Identification of Mental Health Problems in Children's Social Care* (Spark Grant Final Report). What Works for Children's Social Care. <https://whatworks-csc.org.uk/research-report/towards-early-identification-of-mental-health-problems-in-childrens-social-care/>

Parts of the work (i.e. those relating to Ryan Crowley's Master's degree) have also been published in the following journal article:

Crowley, R., **Parkin, K.,** Rocheteau, E., Massou, E., Friedmann, Y., John, A., Sippy, R., Liò, P., & Moore, A. (2025). Machine Learning for Prediction of Childhood Mental Health Problems in Social Care. *BJPsych Open*, 11(3), e86. <https://doi.org/10.1192/bjo.2025.32>

5.2 Acknowledgements

This study makes use of anonymised data held in the Secure Anonymised Information Linkage (SAIL) Databank. I would like to acknowledge all the data providers who make anonymised data available for research. This work was supported by the Adolescent Mental Health Data Platform (ADP). The ADP is funded by MQ Mental Health Research Charity (Grant Reference MQBF/3 ADP). ADP and I would like to acknowledge the data providers who supplied the datasets enabling this research study. The views expressed are entirely my own and should not be assumed to be the same as those of ADP or MQ Mental Health Research Charity.

In addition to my PhD funders, I would like to thank the data funders for this project specifically, WWCS and CPFT, without whom this work would not have been possible, and also everyone mentioned in the Declaration section above, who provided invaluable support.

5.3 Chapter overview

The work in this chapter sought to explore the extent to which it was possible to measure adverse childhood experiences (ACEs) using routinely-collected data, as well as to understand the value of linked, multi-agency data compared to single-agency data in the endeavour of measuring childhood adversity. Here, I present work on characterising databases within the Secure Anonymised Information Linkage (SAIL) Databank, mapping my list of ACEs to the SAIL data dictionaries to create code lists, then using these code lists combined with validated code lists to measure the prevalence of ACEs in a range of routine data sources.

5.4 Introduction

In numerous serious incident reviews involving the death or significant harm of a child, the lessons learnt repeatedly identify a lack of communication or joined-up working between organisations (A. Jones, 2009; Laming, 2003; Maddocks, 2013; The Child Safeguarding Practice Review Panel, 2022). Often, some level of potential risk to the child was known about by at least one part of ‘the system’ in which a young person comes into contact during their daily life, but actual harm was allowed to occur in part because the rest of the system was unaware of prior warning signs. Relatedly, there may be multiple organisations in the system aware of risk or actual harm to a child, and if their awareness of different events were pieced together, this would be a strong enough signal of risk to warrant intervention (The Child Safeguarding Practice Review Panel, 2022). For example, perhaps the GP is supporting the child’s mother for severe depression, but unaware that a social work assessment was carried out due to an incident of domestic violence by the father, nor that a teacher has started to notice the child acting out and behaving differently in class. In isolation, these events may not have been cause for additional support, because each part of the system of care surrounding the child is unaware of others’ concerns, the cumulative magnitude of events, or their potential impact on the child’s health and wellbeing. Additional support is rarely withheld due to ill intent or negligence, but simply because key information is recorded in different parts of the system, in data siloes (Burgan et al., 2017; White, George, & Bourne, 2016), and no-one has oversight of the whole system to view the child more holistically and in context (The Child Safeguarding Practice Review Panel, 2022). As such, professionals work with the information to which they have access and take actions accordingly.

ACEs are known to be associated with various poor outcomes (Center for Disease Control and Prevention, 2019; Felitti et al., 1998; Nelson et al., 2020), so perhaps could be used to help identify mental health problems earlier to target support early and proportionately. However, first this

requires a robust method of identifying and measuring ACEs in a timely way. I hypothesise that better measurement of young people's exposure to ACEs could in future help optimise the early identification of mental health problems, as well as facilitate timely and proportionate support.

Studies have sought to measure ACEs in a variety of different ways, including retrospective reports by adults, surveying people (in adulthood or childhood), and using research data to understand their prevalence. However, these methods have a number of disadvantages. For example, Hardt and Rutter found that retrospective recall of ACEs by adults resulted in high rates of false negatives and measurement error when ACE exposure was cross-validated against other sources; this occurred even for ACEs that could be operationalised well (Hardt & Rutter, 2004). Surveys can be administered with adults in later life, or with young people as they are growing up, meaning the results could be more contemporaneous and relevant for tailoring early support. However, surveys have the downside of being costly and time- and resource-intensive to administer, as well as burdensome for people to complete, which is of particular concern with a sensitive topic like ACEs which may be retraumatising for people (Tourangeau & Yan, 2007). Alternatively, research data have been useful for exploring the prevalence of different ACEs. For example, the Avon Longitudinal Study of Parents and Children database (ALSPAC; aka 'Children of the 90s') was used to measure 19 different adversities (including 10 'classic' adversities), finding relatively comparable rates of ACE exposure to other sources. However, this research included limitations such as being confined to Avon, a former county in the southwest of the UK, reducing its generalisability, and the authors noting that the handling of missing data was a challenge, leading them to assume data were missing-at-random (an untestable assumption) to allow them to use as much data on ACEs as available. Moreover, ALSPAC is known to consist of a population which is predominantly of White ethnicity, and is unlikely to represent other ethnic groups well (A. Fraser et al., 2013). Furthermore, and of great importance to the measurement of ACEs, in the ALSPAC cohort profile, Fraser and colleagues noted attrition in the cohort was greater for mothers who experienced greater adversity at the time of the index pregnancy (the time at which they were recruited to this cohort); this included inadequate housing and lack of social support. The women who attended follow-up assessments for the ALSPAC study tended to be older, less socio-economically-deprived and healthier at recruitment than those who were lost to follow-up, thus posing major questions about the representativeness of the sample (A. Fraser et al., 2013).

An alternative method for better understanding ACEs is to reuse data which is already collected as part of routine service provision in the course of young people's lives. Routinely-collected (or administrative) data from community and acute healthcare, social care and education settings contain

broad-ranging information which could be used to understand an individual's exposure to ACEs. Compared to the other methods noted above, reuse of routine data has the benefit of reducing recall bias, reducing the burden on young people and professionals, and may be more representative of the general population than data collected for research purposes (Soneson et al., 2023; Wickersham & Downs, 2022), with the caveat that some people do not have equal access to statutory services, and there are significant problems with missingness, so this approach would not fully eliminate bias (Kreps, 2017; McFadden et al., 2018; Whitley et al., 2006). The use of routinely-collected data may be further enhanced by linking data together from different statutory services in order to create a more holistic and joined-up picture of a young person's life, as encouraged by the serious case reviews referenced previously. Data linkage could offer an avenue of gaining better system oversight to piece together risk signals surrounding a child and tailor support appropriately (Downs, Gilbert, Hayes, Hotopf, & Ford, 2017; Mental Health Taskforce, 2016; Rees, Fry, Davies, John, & Condon, 2023).

In a scoping review of 121 studies using administrative data linkage to understand and address child maltreatment, it was found that studies using this method fit under eight themes: descriptive epidemiology, risk factors, outcomes, intergenerational transmission, predictive modelling, intervention/ service evaluation, multi-sector involvement, and methodological considerations/advancements (Soneson et al., 2023). For inclusion in the scoping review, studies were required to link at least two data sources (one of which had to be administrative data). The authors noted a number of benefits of administrative data linkage for these purposes, including that datasets may be collected at a population-level, mitigating against selection bias, that they facilitate 'quasi-prospective' analyses, and that valuable contextual information may be available. Alongside these and other benefits, the authors also reflected on a number of limitations of administrative data linkage for understanding childhood maltreatment, including under-reporting, data quality and completeness, lack of researcher control over variables, and the difficulty and time-consuming nature of data access.

An England-focused study used linkage between maternal and child records to develop and validate indicators of ACEs in electronic health record (EHR) data. The study utilised the Clinical Practice Research Datalink (CPRD) data from primary care, hospital episode statistics (i.e. secondary care), and the Office for National Statistics (ONS) mortality register, including data from 211,393 mother-child dyads from up to two years before birth to 5 years post-birth (Syed et al., 2022). The team developed clinically relevant indicators for identifying ACEs using the EHRs of mothers and children who presented to general practices and hospitals. Interestingly, more than 70% of ACEs they identified were detected via the mothers EHR and were recorded in primary care by GPs within 2 years of birth.

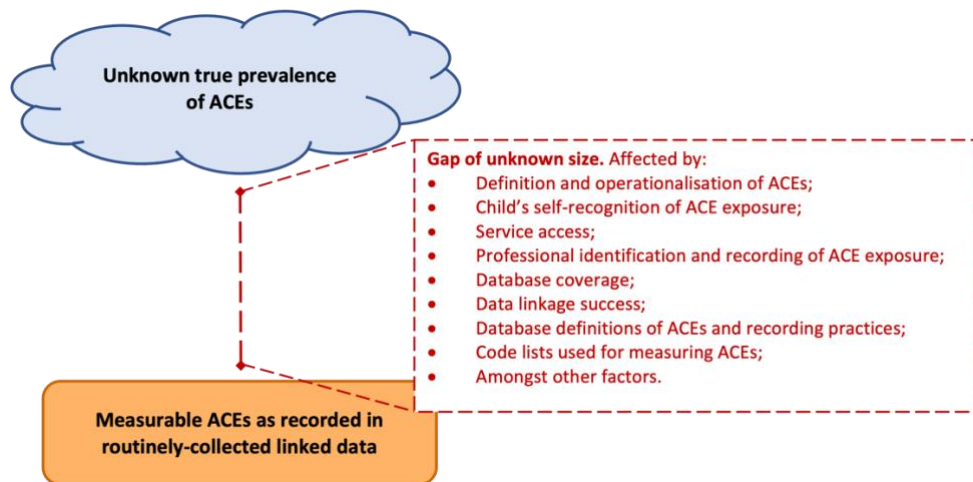
This highlights the potential importance of primary care data and data arising within the early years of a young person's life.

Another team used a retrospective cohort design linking routinely-collected data to understand the risk of intergenerational transmission of child maltreatment from mother to child (Armfield et al., 2021). The researchers linked data from the South Australian Births Registry, Perinatal Statistics Collection, Department for Child Protection, and hospital inpatient and emergency department databases, choosing routine data linkage as a helpful method to explore substantiated reports of maltreatment specifically (as opposed to self-reported cases as would be achieved through surveys of people directly). The study found that children of mothers with any involvement with child protective services (CPS) in childhood had an increased risk of CPS contact compared with those whose mothers had no CPS involvement. However, the authors did note the risk of surveillance bias whereby some of the increased risk of intergenerational transmission of maltreatment could be explained by closer monitoring of mothers known to have a history of CPS involvement themselves, meaning their children's risk is monitored more closely than would otherwise be the case.

This chapter explored the feasibility of measuring different ACEs using routinely-collected data from a multitude of services with which young people interact. As highlighted above, this method has been used by various researchers to gain insights into ACEs and was chosen as a method here because of its various benefits, including reducing recall bias, measuring some substantiated cases of ACEs, and importantly, providing a possible way of measuring ACEs in a more representative or close to whole population way. Given their perceived predictive power, as demonstrated in Chapter 4, if it was possible to robustly measure ACEs using routinely-collected data, this information could be a valuable addition to risk prediction models developed by the Timely team, with the possibility of deploying these models at the point of service delivery when supporting young people. The study explored how many young people with experiences of childhood adversity could be detected in a geographically bound near-whole-population residing in Wales, UK, if routine data sources were linked together. Specifically, the study sought to create a linked database of healthcare, social care and education data in order to measure different ACEs. This provided insights into whether data linkage is a viable part of the solution for identifying young people who might benefit from additional support or cross-agency working. As illustrated in Figure 12, this is based on my supposition that there is an unknown, and basically unknowable, 'true' prevalence of ACEs experienced by young people, and that linked data from administrative sources might cumulatively help get closer to measuring more of the 'truth', with each additionally detected case closing the gap, and being a step closer to this unknown truth.

Routinely-collected linked data, when used in combination with other methods like surveys, could be a method of triangulation on this true prevalence, as each of the methods have their own benefits, blind spots and biases.

Figure 12: Representation of the gap between measurable ACEs and the unknown true prevalence of ACEs, along with factors affecting this gap



5.4.1 Significance of the research

To my knowledge, this is the first study to link so many and such varied administrative data sources together to attempt to measure ACEs. In future, the methods developed here could be applied to other linked databases used for clinical purposes, as well as being used to study the relationship between ACEs and young people's mental health outcomes in administrative data. A linked database is useful for this purpose as it allows ACEs to be measured from different agencies with which young people come into contact, as opposed to limiting measurement to a single agency (such as GP or A&E); this should allow for more comprehensive and holistic measurement of ACEs and associated outcomes. Moreover, though it by no means eliminates bias (ADR UK, 2024b; Hemkens, Contopoulos-loannidis, & Ioannidis, 2016), conducting ACE measurement in routine data, as opposed to research data which has known representation biases (A. Fraser et al., 2013; Gerhard, 2008), is an important contribution of this study. This helps to ensure that young people from different backgrounds benefit from research efforts.

5.4.2 Aims

- To explore the feasibility of measuring ACEs using routinely-collected data;
- To understand the prevalence of different ACEs in the Welsh population according to routinely-collected data;
- To compare single-agency versus multi-agency linked data in order to understand whether linked data have additional value in the measurement of ACEs.

5.5 Methods

5.5.1 Selecting a database

To explore the feasibility of measuring ACEs in routinely-collected data, an appropriate and affordable database first needed to be identified. This work would also be used to help externally validate the CADRE database, thus a comparable database with similar characteristics needed to be identified. Specifically, one that included routinely-collected data from settings such as healthcare, social care, and education, with near-whole-population data.

The main criteria for database selection were potential coverage of ACEs, representativeness of the sample, comparability with the CADRE database in terms of contributing data sources, and the cost of data access. To identify potential databases, I spoke with academics, especially in childhood mental health research, about databases of which they were aware. I met with data providers to better understand their data, its coverage and cost, and then compared these databases with the CADRE database. I compiled a document of the 16 potential databases, their characteristics and cost of access; this document can be accessed online at: [Database Overview on ResearchGate](#).

An abridged version of the database comparisons is shown in Table 19. Based on these comparisons, the Adolescent Mental Health Data Platform, as part of the Secure Anonymised Information Linkage Databank (aka ADP/SAIL) was selected as the most appropriate and complementary database to CADRE. Similarities between SAIL and CADRE included the range and type of data in terms of contributing organisations, participants and character.

Table 19: Abridged version of comparison between various databases and the CADRE database

Database	Health	Education	Social Care	Genetics and biomarkers	Individual-level data	Routinely-collected or research data?	Costs
ADP/SAIL	✓	✓	✓	?	✓	Routinely-collected	£££
Akrivia Health	✓	?	?	?	✗	Routinely-collected	?
ALSPAC	✓	✓	?	✓	✓	Research	£££
Born in Bradford	✓	✓	✓	?	✓	Research	£
CRIS	✓	~	✓	✓	✓	Routinely-collected	Free or £££
ECHILD	✓	✓	✓	?	✓	Routinely-collected	Unavailable
Millennium Cohort Study	✓	✓	?	?	✓	Research	Free
NIHR BioResource	✓	?	?	✓	✓	Research	Unavailable
Understanding Society	✓	✓	?	?✓	✓	Research	Free
WSIC	✓	?✗	✓	?✗	✓	Routinely-collected	Fee for access

ADP/SAIL = Adolescent Mental Health Data Platform/Secure Anonymised Information Linkage Databank; ALSPAC = Avon Longitudinal Study of Parents and Children; CRIS = Clinical Record Interactive Search; ECHILD = Education and Child Health Insights from Linked Data; NIHR = National Institute of Health and Care Research; WSIC = Whole Systems Integrated Care; ? = unknown; ?✗ = unknown but think no; ?✓ = unknown but think yes; ~ = to an extent; £ = small cost; £££ = expensive

5.5.2 Characterising the cohort and databases in the SAIL Databank and working with the data

Once I had chosen the SAIL Databank as an appropriate source of data for the current project, I began characterising the databases to which we had access within the databank in greater detail. Initially, this involved compiling descriptions of how each database was developed and some of the data caveats and limitations (presented in Appendix B.1: Table 57) and describing the coverage of each database (i.e. temporal coverage and cohort coverage). Next, I created code lists for measuring different ACEs and used these in combination with validated code lists from collaborators at the Adolescent Mental Health Data Platform (ADP). I concluded by measuring ACEs based on presence versus absence, by type of ACE, by data source, and by sex. This allowed me to comment on the population, the databases, and data linkage, as well as providing some early insights into unmet need in the system and outcome prediction. A guiding framework was developed for all analysis and reporting of results (shown in Figure 13).

Figure 13: Framework for carrying out analysis and presenting results



Credit: created with draw.io
[\(https://app.diagrams.net/\)](https://app.diagrams.net/).

5.5.3 Population

The baseline cohort was created to both mirror the CADRE (Child and Adolescent Data REsource) database timeframe and to include a timeframe where the most data from relevant SAIL databases were available. The time period identified was between 1 January 2013 and 31 March 2020. The cohort included anyone who was aged 0–17 years in this period; all retrospective and subsequent data for these individuals were then included even if the data fell outside this time period. My final cohort consisted of 1,113,776 young people in Wales, of which 548,673 were female (49.26%), 565,086 were male (50.74%) and 17 were of unknown sex (<0.00%).

5.5.4 Data sources

The SAIL Databank is a national data safe haven of de-identified databases relating to the population of Wales. SAIL operates on the UK Secure Research Platform (UKSeRP). Researchers can apply to access SAIL data in an anonymised form via this secure research environment (K. H. Jones, Ford, Thompson, & Lyons, 2019; Lyons et al., 2009).

18 SAIL databases were identified which would be relevant to this project. These databases were administrative or routinely-collected and broadly pertained to demographics (including births and deaths), social care, education and healthcare (both community and acute). Specifically, the databases and their associated acronyms (which are used throughout this chapter) were as follows:

- Welsh Demographic Service Dataset (WDSD)
- Annual District Birth Extract (ADBE)
- Annual District Death Extract (ADDE)
- Child in Need – Wales (CINW)
- Children Receiving Care and Support (CRCS)
- Looked After Children – Wales (LACW)
- Pre-16 Education Attainment and Attendance – Wales (EDUW)
- Welsh Longitudinal General Practice (WLGP)
- National Community Child Health (NCCH)
- Maternity Indicators Dataset (MIDS)
- Patient Episode Dataset – Wales (PEDW)
- Outpatient Referrals from Primary Care Dataset (OPRD)
- NHS Hospital Outpatients Dataset – Wales (OPDW)
- NHS 111 Call Data (NHSO)
- Emergency Department Dataset (EDDS)
- Critical Care Dataset (CCDS)
- Wales Results Reporting Service (WRRS)
- Substance Misuse Dataset (SMDS).

Detailed descriptions of each database can be found in Appendix B.1 (Table 57), along with some important information and caveats about the data.

5.5.5 Data management and pre-processing

The data used were administrative data collected from healthcare, local authority services (including education provision and social care) and government carrying out their day-to-day duties. No further data were collected for the purpose of this research. As per SAIL requirements, no raw data were stored; all data were accessed via a Virtual Desktop Infrastructure (VDI) and all results were reviewed by SAIL analysts prior to release from the gateway (i.e. the working environment) in order to avoid disclosure/reidentification of individuals.

Before data are incorporated into the SAIL Databank, data providers (e.g. GPs, hospitals, government departments, etc) separate their databases into two parts: a demographic component and a content component. Content information is sent directly to SAIL, while demographic information is processed by a National Health Service-based Trusted Third Party in the NHS Wales Informatics Service (NWIS). Only Anonymised Linkage Fields (ALFs, i.e. unique identifiers) with some minimal demographic data (including gender, week of birth and general area of residence) are sent to SAIL for recombination with the content data. SAIL does not have access to or control over patient identifiable data; therefore SAIL does not become a data controller (K. H. Jones et al., 2019). The Health Information Research Unit (HIRU) is the data custodian, but there is shared control over access and use of the data through an IGRP (Information Governance Review Panel) (D. V. Ford et al., 2009).

All data are treated in accordance with the Data Protection Act 2018. According to Jones and colleagues (2019):

“SAIL is not required to seek additional consent to incorporate datasets arising from routine public service delivery. This is because it is not a research activity per se and data accessed by researchers are in anonymised form. In accordance with the GDPR, [they] provide privacy notices on behalf of data providers (in places such as in General Practice surgeries). These inform members of the public of data use, and individuals are able to opt-out of their data being provided to SAIL by informing their GP. The opt-out is enacted between the data provider and NWIS: in practice [SAIL] have had less than 0.025% of the population make this request to date.”

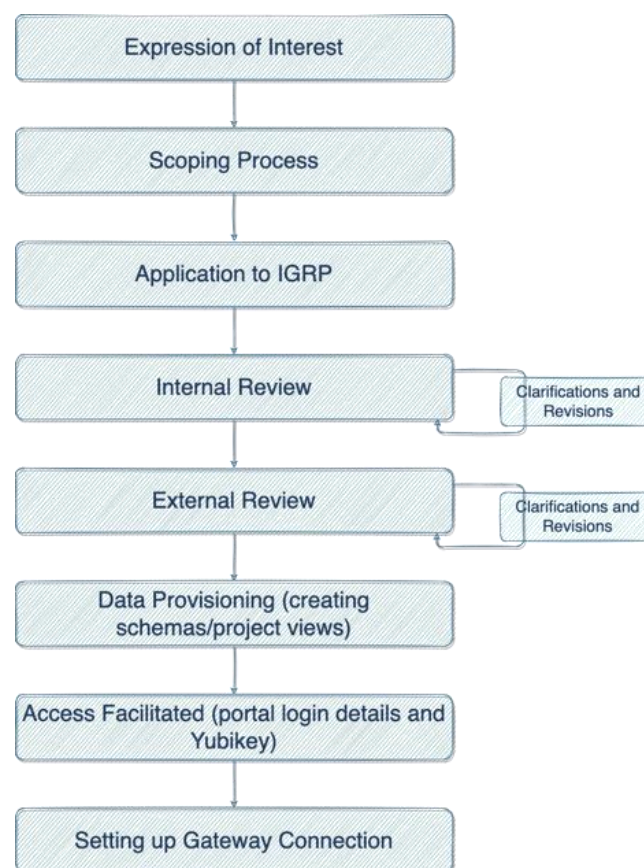
For the most part, the data provisioned to researchers by SAIL are very similar to the original unprocessed data available to clinicians and professionals in routine practice, but with unstructured (i.e. free-text notes) omitted. According to the SAIL support team, there is some minimal data processing that happens for the WDSD, PEDW and WLGP (for example, with the WLGP, the GP registration records for individuals are simplified and anomalies such as short gaps and overlaps are

resolved by applying a set of rules; (see Thayer et al. (2020) for details). However, other than this, the SAIL team tends to provide data to researchers as they are received from data providers. The SAIL team can make recommendations to researchers about data cleaning and processing, but generally the process of data cleaning is left to researchers as each project will have unique requirements (personal communication, 13 December 2022). More detailed information about each database, including time lags for incorporation into SAIL, can be found on the HDRUK website by searching per database⁵.

5.5.6 Data access and information governance

Data access was granted according to the SAIL ethics process. The application was reviewed by their internal and external review panel (i.e. IGRP), which includes representatives from Informing Healthcare, the National Research Ethics Service, the National Public Health Service for Wales, the British Medical Association and Involving People (D. V. Ford et al., 2009). The full access process is illustrated in Figure 14.

Figure 14: Flowchart of access process for SAIL



Credit: created with draw.io
<https://app.diagrams.net/>.

⁵ <https://www.healthdatagateway.org/>

5.5.7 A note to the reader: reporting small-value results

To mitigate against reidentification of individuals, SAIL stipulates that any reported results must include a minimum of five individuals (and a minimum of ten individuals for data from the Office for National Statistics census, which was not included in the present project). Results smaller than this must be aggregated. Where this occurred, I have indicated it with the value <5, the symbol * and an explanatory note. The exception to this rule was when masking of small values occurred inherently through data missingness. For example, if <5 people were of unknown sex, the true value could be reported as individuals' identity was masked by the missingness of sex data.

5.5.8 Data linkage

When data are incorporated into the SAIL Databank, individuals within databases are assigned a unique Anonymised Linkage Field (ALF) that replaces any identifiable information, such as names, and enables anonymised linkage across the different databases. ALF assignment is completed by deterministic record linkage if NHS numbers are available and then probabilistic record linkage if deterministic record linkage is not possible. Additional technical details are provided in Appendix B.5 and the full process is detailed by Lyons and colleagues (2009) (see in particular Figure 1, pg. 7). According to Ford, Lyons and colleagues, the optimum matching technique was found to yield specificity values >99.8% and sensitivity values >94.6% with probabilistic record linkage at the 50% threshold, with error rates of <0.2% (D. V. Ford et al., 2009; Lyons et al., 2009). The public are able to opt-out of their data being included in the databank should they wish but, as of 2019, SAIL had had less than 0.025% of the population make this request, implying high representativeness in the data (K. H. Jones et al., 2019).

For the present study specifically, data were linked on an individual level via the ADP. The data linkage process matched individuals' records between databases and facilitated de-duplication of individuals' records. Linkage of individuals was carried out across 18 databases (with multiple schemas (or tables) per database). Where ALFs were available in databases and schemas, these were used to link individuals. However, some databases did not contain ALFs, so corresponding ALFs were attached to individuals' records in these databases based on other identifiers, such as pupil ID (for linking the education database), client ID and child ID (for linking the national community child health database), maternal ID (for linking the maternal indicators database), local authority code and child code, as well as the 'IRN_PE' code which linked to the education database (for linking the social care databases).

5.5.9 Characterising available databases

Each of the 18 databases were characterised (presented in Appendix B.1: Table 57) and the team explored the proportion of individuals from the baseline cohort present in each database (presented in Table 22).

Table 20 shows how we chose to group the databases together for the purpose of describing data sources and, where appropriate, presenting results in subsequent sections. These groupings are simply to aid the reader's understanding and interpretation of results. They are our team's conceptualisation of groupings based on the characteristic similarities of the data sources, rather than reflecting true groupings between databases.

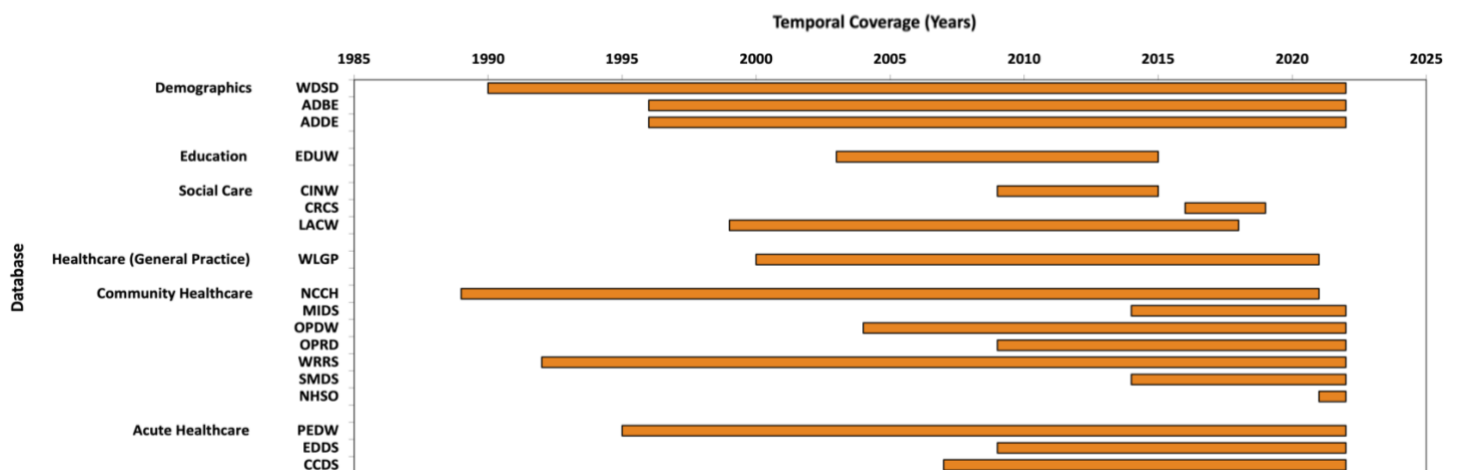
Table 20: Database groupings for presentation purposes

Group name	Individual data sources
Demographics	Welsh Demographic Service Dataset (WDSD) Annual District Birth Extract (ADBE) Annual District Death Extract (ADDE)
Education	Pre-16 Education Attainment and Attendance – Wales (EDUW)
Social Care	Child In Need – Wales (CINW) Children Receiving Care and Support (CRCS) Looked After Children – Wales (LACW)
Healthcare (General Practice)	Welsh Longitudinal General Practice (WLGP)
Community Healthcare	National Community Child Health (NCCH) Maternity Indicators Dataset (MIDS) NHS Hospital Outpatients Dataset – Wales (OPDW) Outpatient Referrals from Primary Care Dataset (OPRD) Wales Results Reporting Service (WRRS) Substance Misuse Dataset (SMDS) NHS 111 Call Data (NHSO)
Acute Healthcare	Patient Episode Dataset – Wales (PEDW) Emergency Department Dataset (EDDS) Critical Care Dataset (CCDS)

For a detailed description of each of the 18 databases, refer to Appendix B.1: Table 57. This provides an understanding of how the cohort for each database was created and how young people became part of a database.

Figure 15 and Table 21 show the rough temporal coverage of each included database. Of note, this is data provided by SAIL for all of their databases, not specifically for our databases. It is presented here to show the variety of temporal coverage per database and highlight periods of time where databases do, or do not, overlap. For the present project, all available data were used; thus, the cohort consisted of all data available for anyone who was aged 0 to 17 years in the time period 1 January 2013 to 31 March 2020 (all retrospective and subsequent data for these individuals was included even if it fell outside this time period).

Figure 15: Temporal coverage of the 18 databases



Credit: created with Microsoft Excel.

Table 21: Temporal coverage of the 18 databases

Database type	Database	Start date	End date
Demographics	WDSD	01/01/1990	28/03/2022
	ADBE	01/01/1996	26/10/2022
	ADDE	01/01/1996	01/03/2022
Education	EDUW	01/01/2003	31/12/2015
Social Care	CINW	01/03/2009	31/03/2015
	CRCS	01/04/2016	31/05/2019
	LACW	21/06/1999	31/03/2018
Healthcare (General Practice)	WLGP	01/01/2000	21/08/2021
Community Healthcare	NCCH	01/01/1989	28/06/2021
	MIDS	01/04/2014	16/03/2022
	OPDW	01/04/2004	01/03/2022
	OPRD	01/04/2009	01/03/2022
	WRRS	01/06/1992	29/01/2022
	SMDS	01/04/2014	02/02/2022
	NHSO	02/08/2021	04/02/2022
Acute Healthcare	PEDW	01/04/1995	28/03/2022
	EDDS	01/04/2009	01/03/2022
	CCDS	01/01/2007	01/03/2022

Table 22 shows how many young people were present in each database and what proportion of the whole cohort this equates to.

Table 22: Number and percentage of individuals from Timely team cohort present in each database

Database type	Database name	Number of individuals	% of cohort
Demographics	Welsh Demographic Service Dataset (WDSD)	1,113,776	100
	Annual District Birth Extract (ADBE)	800,714	71.89
	Annual District Death Extract (ADDE)	2,400	0.22
Education	Pre-16 Education Attainment and Attendance – Wales (EDUW)	766,250	68.80
Social Care	Child In Need – Wales (CINW)	35,481	3.19
	Children Receiving Care and Support (CRCS)	26,653	2.39
	Looked After Children – Wales (LACW)	7,363	0.66
Healthcare (General Practice)	Welsh Longitudinal General Practice (WLGP)	944,933 - 1,095,022*	84.84 - 98.32*
Community Healthcare	National Community Child Health (NCCH)	290,391 - 999,375*	26.07 - 89.73*
	Maternal Indicators Dataset (MIDS)	173,134	15.54
	NHS Hospital Outpatients Dataset – Wales (OPDW)	694,418	62.35
	Outpatient Referrals from Primary Care Dataset (OPRD)	629,193	56.49
	Wales Results Reporting Service (WRRS)	876,039 - 877,005*	78.65 - 78.74*
	Substance Misuse Dataset (SMDS)	4,604 - 11,545*	0.41 - 1.04*
	NHS 111 Call Data (NHSO)	165,790	14.89
Acute Healthcare	Patient Episode Dataset – Wales (PEDW)	629,904	56.56
	Emergency Department Dataset (EDDS)	710,752	63.81
	Critical Care Dataset (CCDS)	2,043	0.18

*Some of the databases were made of sub-databases (called schemas) so contain a range of individuals depending on the specific schema used within the database.

5.5.10 Code lists

5.5.10.1 *Code lists I developed and operationalised*

After characterising the databases, ACEs were mapped to the variables available in SAIL using the data dictionaries for the 18 databases. Some variables mapped to multiple ACEs and, at times, a best proxy was used. A summary of the mapping is reported in Appendix B.2 (Table 58). Of note, this was my proposed (theoretical) way of measuring ACEs within each of these databases. However, when I measured them, some variables were unusable (e.g. legacy variables, inaccurate variable descriptions, or predominantly null values).

The code lists were then operationalised by identifying the values that would indicate ACE exposure, per variable. Where multiple responses within a variable indicated an ACE (e.g. 'urgent housing problem' or 'no fixed abode' both indicated homelessness within the variable 'housing status'), they were re-categorised into a binary value (presence or absence of an ACE). A spreadsheet was created with all mapped variables and a column of values indicating ACE exposure, and one indicating no ACE exposure. SQL code was written to identify the children who were exposed to ACEs (described in Section 5.5.11).

5.5.10.2 *Code lists from collaborators (ADP)*

Whilst working with the SAIL Databank, our team developed a collaboration with the Adolescent Mental Health Data Platform (ADP), and this team also shared code lists they had created and validated for measuring confirmed maltreatment and possible (i.e. suspected or inferred) cases of maltreatment (John et al., in press). With permission, I used these validated code lists in combination with the ACEs I had mapped against the SAIL metadata, in order to enhance my measurement of ACEs. A description of how the ADP developed the code lists for confirmed and possible maltreatment is included in Appendix B.3.

5.5.11 Methods for measuring ACEs

Combining the code lists developed by myself and the ADP, it was theoretically possible to measure 11 out of 18 intended ACEs within SAIL; Table 23 shows which ACEs were measurable and which were not. The table also shows in which specific databases they could be measured. Of note, for the remainder of this chapter, the term 'maltreatment' is used in place of 'abuse' to be consistent with the naming of the ADP's maltreatment code lists; however, this is synonymous with abuse here.

Table 23: Table of measurable versus unmeasurable ACEs within the SAIL databases, and details of which data sources could be used to measure each ACE

		Measurable (Yes/No)	Data Source																	
			Demographics			Education	Social Care			Healthcare										
			WDS	ADBE	ADDE	EDUW	CINW	CRCS	LACW	WLGP	NCCH	MIDS	OPDW	OPRD	WRRS	SMDS	NHSO	PEDW	EDDS	CCDS
ACE type	Physical maltreatment	Yes	x	x	✓	x	✓	✓	x	✓	x	x	✓	x	✓	x	x	✓	✓	x
	Sexual maltreatment	Yes	x	x	✓	x	x	✓	x	✓	✓	x	✓	x	✓	x	x	✓	✓	x
	Psychological maltreatment	Yes	x	x	✓	x	x	✓	x	✓	x	x	✓	x	✓	x	x	✓	✓	x
	Financial maltreatment	Yes	x	x	x	x	x	✓	x	✓	x	x	x	x	✓	x	x	x	x	x
	Parent or guardian IPV	Yes	x	x	x	x	✓	✓	x	✓	x	x	x	x	✓	x	x	x	x	x
	Other maltreatment*	Yes	x	x	✓	x	✓	✓	✓	✓	✓	x	✓	x	✓	x	x	✓	✓	x
	Neglect	Yes	x	x	✓	x	✓	✓	✓	✓	x	x	✓	x	✓	x	x	✓	✓	x
	Parent or guardian in prison or on probation	No	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x
	Parent or guardian mental health problems	Yes	x	x	x	x	✓	✓	x	x	x	✓	x	x	x	x	x	x	x	x
	Parent or guardian substance misuse	Yes	x	x	✓	x	✓	✓	x	x	x	x	✓	x	x	x	x	✓	✓	x
	Parental separation or divorce	No	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x
	Death of a parent or guardian	No	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x
	Involvement with CPS or living in care	Yes	x	x	✓	x	✓	✓	✓	✓	✓	x	✓	x	✓	x	x	✓	✓	x
	Homelessness or unstable housing	Yes	x	x	x	x	✓	✓	✓	x	x	x	x	x	x	✓	x	x	x	x
	Experiencing bullying	No	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x
	Experiencing racism	No	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x
	Experiencing violence in the community	No	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x
	Being a young carer	No	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x

IPV = interpersonal violence; CPS = child protective services; **Yes** = ACE was measurable in at least 1 database within SAIL; **No** = ACE was not measurable in any database within SAIL; ✓ = measurable within this database; x = not measurable within this database; * = 'Other maltreatment' was not part of original ACE categories but emerged as a catch-all group to capture ACEs that did not clearly fit into specific maltreatment categories.

To measure ACEs within SAIL, SQL queries were developed based on the operationalised code lists. Below is an overview of the methods used to measure ACEs; a more detailed version is included in Appendix B.4, supplemented with code snippets to aid explanation.

Step 1: Using the code lists I had developed and operationalised, for each database, tables were created (known as views) with only the young people who had experienced ACEs (i.e. positive cases only). The number of unique individuals were counted, using their unique identifier (aka ALF).

Step 2: Step 1 was repeated using the ADP code lists, creating views divided into 'confirmed' or 'suspected' cases, in accordance with how these code lists were created. A 'combined' view was also created, containing both confirmed and suspected cases, to measure any possible ACEs per database. Again, the number of unique young people per database who had experienced any ACE were counted.

Steps 1 and 2 allowed measurement of the prevalence of exposure to any ACE per database (i.e. how many people per database had ≥ 1 ACE), but did not identify which particular ACEs were experienced by young people, nor which databases captured certain ACEs over others. Subsequent steps addressed this.

Step 3: A spreadsheet was created with tabs of specific code lists per ACE and how that ACE could be measured in each of the databases in which it was measurable. Due to its size (706 rows in the longest sheet), the spreadsheet is not included in this thesis; however, it can be provided upon request.

Each list of ACEs (i.e. tab in the spreadsheet) was turned into a text file, resulting in 11 text files of measurable ACEs. ChatGPT was used to assist with formatting these text files (i.e. transforming the lists of several hundred codes into the correct syntax with apostrophes and commas separating codes); these files were then manually checked line-by-line to avoid any errors. The 11 ACEs were:

- Physical maltreatment
- Psychological maltreatment
- Sexual maltreatment
- Financial maltreatment
- Neglect
- Other maltreatment
- Parent or guardian interpersonal violence (IPV)
- Parent or guardian mental health problems

- Parent or guardian substance misuse problems
- Homelessness or unstable housing
- Involvement with child protective services (CPS) or living in care

Using these text files, SQL code was written which made views of only the ALFs where ACEs were positive (i.e. an ACE occurred) by ACE type by database (e.g. CINW_NEGLECT, a view containing all instances of a young person with a code from the CINW database indicating they had experienced neglect). This process resulted in 72 views i.e. a view for every database where it was possible to measure each ACE, with a view per ACE type.

Step 4: Using the 72 views created in step 3, unique ALFs (i.e. unique individuals) were counted to measure how many people had experienced each ACE per database. This provided a portion of the results i.e. ACEs by type by database.

Step 5: To calculate the population prevalence of each ACE, the SQL views were converted into tables, allowing them to be altered, then event flags were added (specifying in which database the ACE was measured). Using a union function, the tables for each ACE were combined and unique ALFs were counted. This gave the result of how many young people had experienced each ACE regardless of database. This was repeated per ACE type, resulting in one table for each ACE type, allowing measurement of the total number of young people to have experienced each ACE.

Step 6: To measure the prevalence of any ACE in the population (regardless of ACE type or database), a linked database was created using the tables made in step 5. The linked database was created by left joining each of the tables from step 5 onto the WDS, i.e. the baseline cohort database which contained all ALFs. Each ACE count was checked to ensure it matched with results from step 5. In a later step (step 8), the totals were counted.

Step 7: To understand how many cases of ACE exposure were measured in each database, the linked database was used and unique ALFs were counted where each given database was the source of that ACE being measured (e.g. the unique young people who had any of the ACEs recorded in the PEDW database). This was repeated for each database, providing totals per database.

Step 8: Using the linked database created in step 6, the total number of young people exposed to any ACE was counted (counting unique cases where any of the ACE types was 'NOT NULL').

Step 9: Finally, the script above was re-run, grouped by sex to get counts broken down by girls, boys and people of unknown sex. This was done per ACE regardless of database and per ACE by database. In addition, this was repeated per database regardless of ACE exposure, in order to understand what the sex composition was of each database (i.e. to characterise the database). Of note, if disaggregating by sex would reveal numbers below 5, these numbers were masked (e.g. aggregated) to avoid risking reidentification. Where this was the case, it is flagged in the Results section.

5.6 Results

5.6.1 Basic demographic information

Basic demographic information for the databases used in the ACE measurement exercise are presented in Table 24. The split of girls and boys in the baseline cohort database (WDSD) aligns with the sex division of this age group in the most recent census for Wales in 2021 (Office for National Statistics, 2022). Of note, ethnicity data were not available for the whole cohort (only for the social care databases), so this is not reported.

Table 24: Number and percentage of young people in my cohort (broken down by sex) in each database

Database type	Database	N of girls (% of database)	N of boys (% of database)	N of unknown sex (% of database)	Total*
Demographics	WDS	548,673 (49.26)	565,086 (50.74)	17 (<0.00)	1,113,776
	ADDE	970 (40.89)	1,402 (59.11)	0 (0.00)	2,372
Social Care	CINW	14,307 (45.51)	17,127 (54.48)	1 (<0.00)	31,435
	CRCS	12,003 (46.09)	14,038 (53.91)	0 (0.00)	26,041
	LACW	6,179 (47.08)	6,945 (52.92)	0 (0.00)	13,124
Healthcare (General Practice)	WLGP	467,501 (49.38)	479,239 (50.62)	13 (<0.00)	946,753
Community Healthcare	NCCH	127,784 (48.84)	133,872 (51.16)	2 (<0.00)	261,658
	MIDS	84,686 (48.91)	88,447 (51.09)	1 (<0.00)	173,134
	OPDW	313,418 (47.57)	345,465 (52.43)	7 (<0.00)	658,890
	WRRS	435,481 (49.66)	441,513 (50.34)	11 (<0.00)	877,005
	SMDS	3,352 (36.23)	5,900 (63.77)	0 (0.00)	9,252
Acute Healthcare	PEDW	295,843 (47.09)	332,422 (52.91)	7 (<0.00)	628,272
	EDDS	335,505 (47.24)	374,763 (52.76)	0 (0.00)	710,275

* = Some of the database totals for my cohort differ from those in the Timely team cohort initial database characterisation presented in Table 22. This could be as a result of which schema was used for database characterisation, to do with the data linkage process, or due to some other reason.

WDS = Welsh Demographic Service Dataset; **ADDE** = Annual District Death Extract; **CINW** = Child In Need – Wales; **CRCS** = Children Receiving Care and Support; **LACW** = Looked After Children – Wales; **WLGP** = Welsh Longitudinal General Practice; **NCCH** = National Community Child Health; **MIDS** = Maternal Indicators Dataset; **OPDW** = NHS Hospital Outpatients Dataset – Wales; **WRRS** = Wales Results Reporting Service; **SMDS** = Substance Misuse Dataset; **PEDW** = Patient Episode Dataset – Wales; **EDDS** = Emergency Department Dataset

5.6.2 Measurability of ACEs

Of the ACEs this study aimed to measure, the variable mapping exercise described in the methods above led to the conclusion that it was theoretically possible to measure only 11, namely: 1) physical maltreatment; 2) psychological maltreatment; 3) sexual maltreatment; 4) financial maltreatment; 5)

neglect; 6) other maltreatment; 7) parent or guardian interpersonal violence (IPV); 8) parent or guardian mental health problems; 9) parent or guardian substance misuse problems; 10) homelessness or unstable housing; and 11) involvement with child protective services (CPS) or living in care. The category 'other maltreatment' was also an additional one which had not been anticipated; this incorporated ACEs which did not clearly fit into a specific category but were a clear indication of exposure to an ACE, such as codes like 'personal history of unspecified abuse in childhood'. At the time of analysis, no variables within the available SAIL databases adequately mapped to: 1) a parent or guardian being in prison or on probation; 2) parental separation or divorce; 3) death of a parent or guardian; 4) experiencing bullying; 5) experiencing racism; 6) experiencing violence in the community; or 7) being a young carer.

5.6.3 Main findings

As per the 'Five Pillars of Analysis' set out in the Methods section (Figure 13), the results are presented in terms of what can be learnt about: 1) the Population; 2) the Database; 3) Data Linkage; 4) Unmet Need; and 5) Prediction of Mental Health Problems.

5.6.3.1 Population

This section focuses on what can be learnt about the population of young people in Wales in terms of their exposure to ACEs according to routine data. The Welsh Demographic Service Dataset (WDSD), which was used as the baseline database for constructing a cohort, consisted of 1,113,776 young people. This baseline cohort broke down into 548,673 girls (49.26%), 565,086 boys (50.74%) and 17 people of unknown sex (<0.00%). All analyses in this chapter attempted to measure recorded ACE exposure in this baseline cohort of more than a million young people.

Of the 1,113,776 young people in the baseline cohort, 15.14% (n=168,660) had a recorded experience of at least one ACE; this comprised 7.14% (n=79,490) girls, 8.01% (n=89,166) boys, and <0.00% (n=4) of unknown sex. Therefore, of all the girls who could have had a recorded ACE, 14.49% did (i.e. 79,490 girls of a possible 548,673). Of all possible boys in the cohort, 15.78% had a recorded ACE (i.e. 89,166 boys of a possible 565,086). Finally, of all the people where sex was unknown, 23.53% had a recorded ACE (i.e. 4 young people of unknown sex of a possible 17). When a chi-square test of independence was performed to examine the relationship between a person's sex and recorded exposure of an ACE (excluding those of unknown sex), the relationship between these variables was statistically significant ($\chi^2 = 361.35$, $df = 1$, $p < .00001$). Boys were more likely than girls to have a recorded experience of at least one ACE.

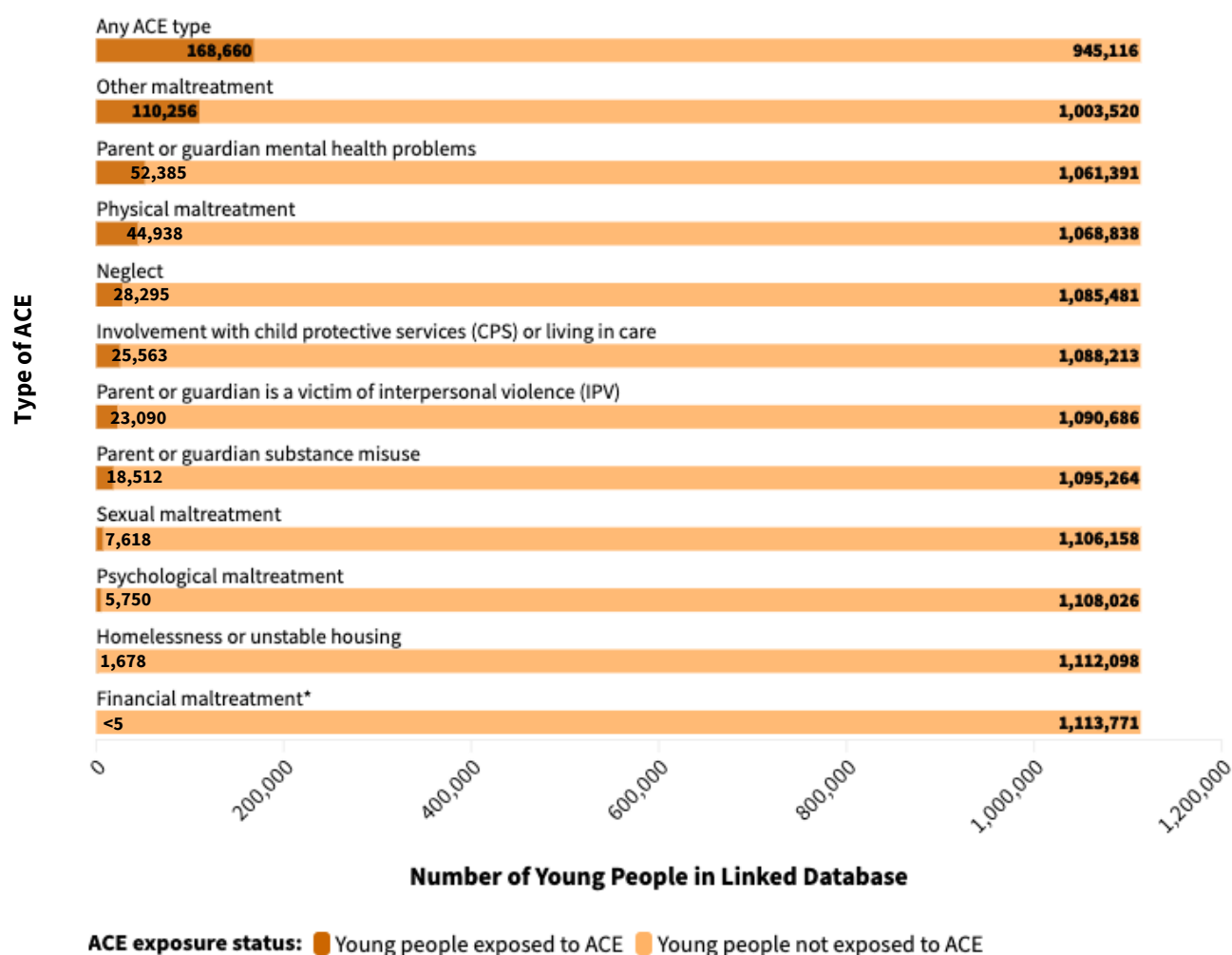
The prevalence of each ACE is presented in tabular and graphical form below (Table 25 and Figure 16). The most commonly recorded ACE was 'other maltreatment', with 9.9% (n=110,256) of the baseline cohort experiencing this. As a reminder, 'other maltreatment' consisted of codes which did not clearly fit into specific ACE categories but indicated such exposures; for example, 'maltreatment syndromes', 'personal history of unspecified abuse in childhood', and 'subject of marac | subject of multi-agency risk assessment conference'. The second most commonly recorded ACE was 'parent or guardian mental health problems' and was just half as prevalent (4.7%, n=52,385). The least frequently recorded ACE was 'financial maltreatment', recorded as being experienced by <0.001% (n=<5).

Table 25: Number of young people exposed to each ACE type, regardless of database

ACE type	N of young people who experienced each ACE	ACE prevalence as % of baseline cohort*
Other maltreatment	110,256	9.90
Parent or guardian mental health problems	52,385	4.70
Physical maltreatment	44,938	4.03
Neglect	28,295	2.54
Involvement with child protective services (CPS) or living in care	25,563	2.30
Parent or guardian is a victim of interpersonal violence (IPV)	23,090	2.07
Parent or guardian substance misuse	18,512	1.66
Sexual maltreatment	7,618	0.68
Psychological maltreatment	5,750	0.52
Homelessness or unstable housing	1,678	0.15
Financial maltreatment	<5	<0.001
Any ACE type (i.e. ≥1 ACE)	168,660	15.14

* **Reminder:** the baseline cohort of young people was 1,113,776; this was used as the denominator for calculating this prevalence.

Figure 16: Prevalence of different ACEs experienced by young people in the linked database, in descending order



* Numbers of <5 are aggregated to 5 to reduce the risk of reidentification.

Credit: created with flourish.studio (<https://flourish.studio>).

In terms of exposure to ACEs broken down by sex, two ACEs were more commonly recorded in girls than boys; these were psychological maltreatment and sexual maltreatment. The remaining eight ACEs were more commonly recorded in boys than girls (see Table 26 for details). Given the coding scheme for sex was binary, plus a 'missing' category where sex was unknown, this analysis did not allow for commentary on ACEs experienced by young people who identified as non-binary. Exposure to each ACE is also presented graphically by sex in two ways: as a proportion (percentage) of all young people exposed (in Figure 17); and also as number of young people exposed (in Figure 18), in order to reflect the differing prevalences of each ACE type.

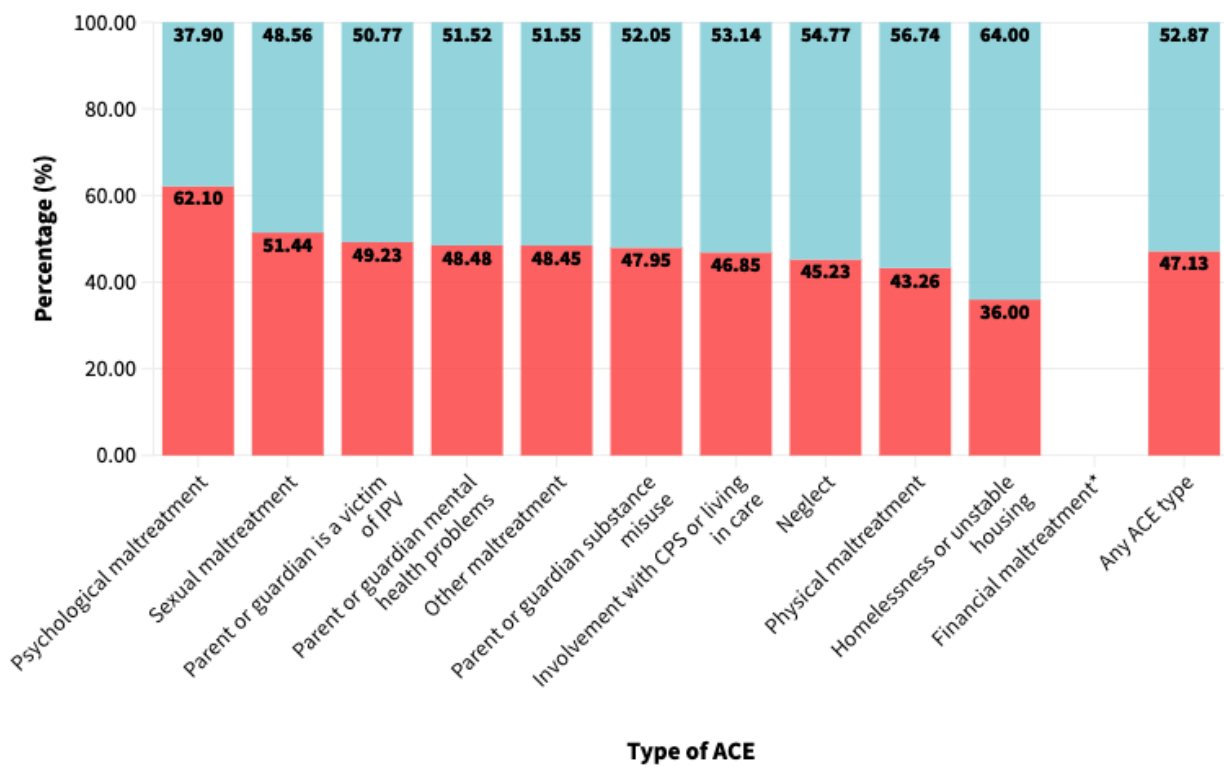
Table 26: Number of young people exposed to each ACE type, broken down by sex

ACE type	N of girls (% of total exposed)	N of boys (% of total exposed)	N of unknown sex (% of total exposed)	Total
Neglect	12,798 (45.23)	15,496 (54.77)	1 (>0.00)	28,295 (100)
Physical maltreatment	19,438 (43.26)	25,497 (56.74)	3 (>0.00)	44,938 (100)
Financial maltreatment	* (N/A)	* (N/A)	* (N/A)	<5 (100)
Psychological maltreatment	3,571 (62.10)	2,179 (37.90)	0 (0.00)	5,750 (100)
Sexual maltreatment	3,919 (51.44)	3,699 (48.56)	0 (0.00)	7,618 (100)
Other maltreatment	53,420 (48.45)	56,834 (51.55)	2 (>0.00)	110,256 (100)
Parent or guardian mental health problems	25,395 (48.48)	26,990 (51.52)	0 (0.00)	52,385 (100)
Parent or guardian substance misuse	8,876 (47.95)	9,636 (52.05)	0 (0.00)	18,512 (100)
Parent or guardian is a victim of interpersonal violence (IPV)	11,367 (49.23)	11,722 (50.77)	1 (>0.00)	23,090 (100)
Homelessness or unstable housing	604 (36.00)	1,074 (64.00)	0 (0.00)	1,678 (100)
Involvement with child protective services (CPS) or living in care	11,977 (46.85)	13,585 (53.14)	1 (>0.00)	25,563 (100)
Any ACE	79,490 (47.13)	89,166 (52.87)	4 (>0.00)	168,660 (100)

* = Actual value is masked in order to comply with SAIL's rules on reporting of small numbers. The threshold for masking is undisclosed and the value can be 0.

Rationale for masking: values masked to provide ambiguity about where numbers fall if they are <5 (using * symbol across multiple categories if the category range of included values in <5 would not include all values of 1-4). Of note, SAIL analysts advised that missing values <5 can be reported (i.e. within 'unknown sex' column) because they are inherently masked already by virtue of being missing.

Figure 17: Girls versus boys exposed to each ACE type, presented as proportions of exposure



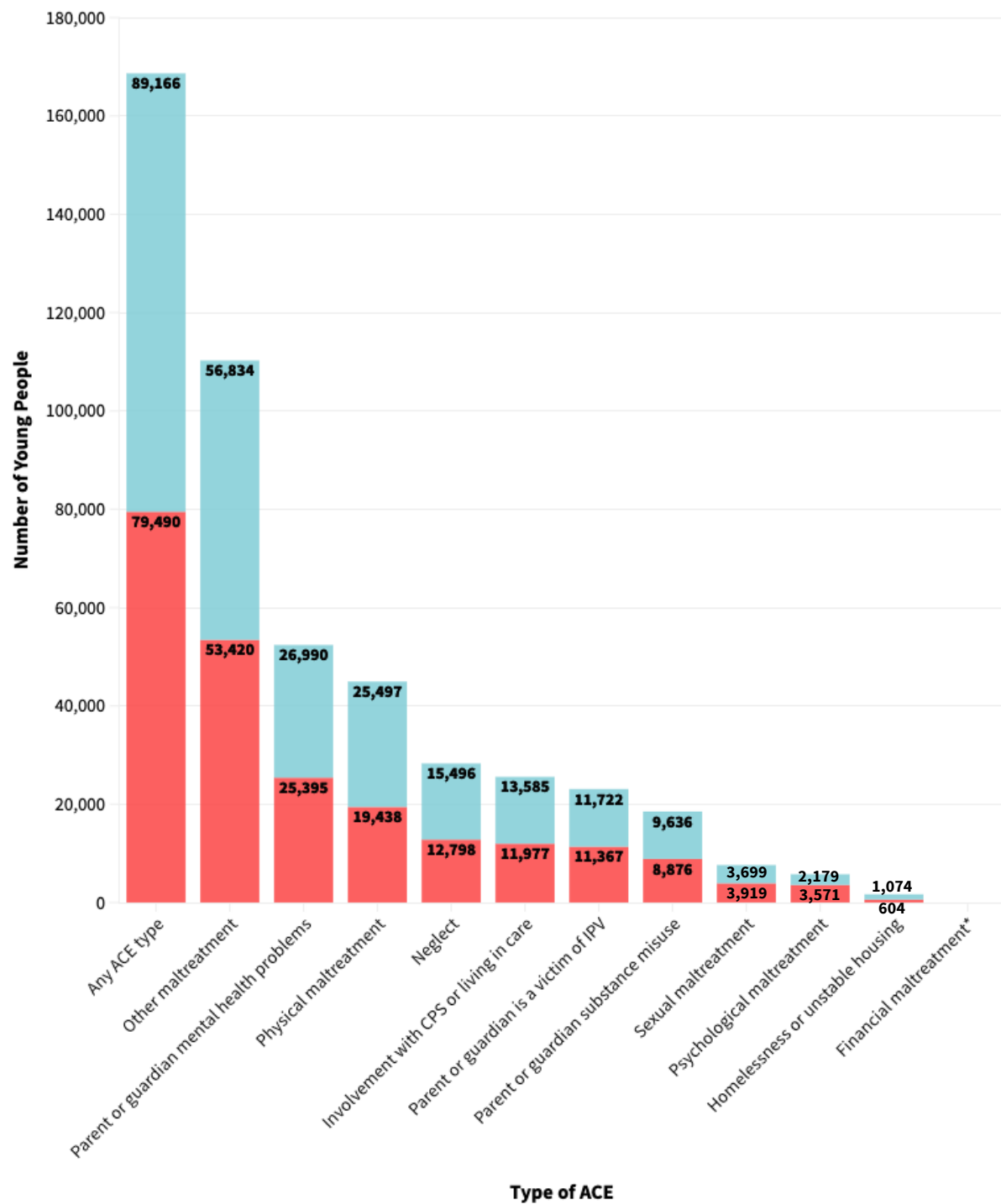
Sex of young people: ■ Girls ■ Boys ■ Unknown sex

* Numbers of <5 cannot be disaggregated due to the risk of reidentification.

IPV = interpersonal violence; CPS = child protective services

Credit: created with flourish.studio (<https://flourish.studio>).

Figure 18: Girls versus boys exposed to each ACE type, presented as total number of people exposed



Sex of young people: ■ Girls ■ Boys ■ Unknown sex

* Numbers of <5 cannot be disaggregated due to the risk of reidentification.

CPS = child protective services; IPV = interpersonal violence

Credit: created with flourish.studio (<https://flourish.studio>).

5.6.3.2 Database

This section focuses on what can be learnt about the utility of each database for the measurement of ACEs. The linked database was made up of 49.26% girls (n=548,673), 50.74% boys (n=565,086), and <0.00% with an unknown sex (n=17). However, each database comprising it had a different number of young people present. For example, excluding the baseline database (aka WDSD), the GP database (WLGP) was the largest database, with 946,753 young people (85% of the baseline cohort). The smallest database, the death registry (ADDE), had just 2,372 young people (0.2% of the baseline cohort). Of note, the databases had existed or been available to SAIL for differing number of years (as demonstrated in the Methods section; see Figure 15), in part accounting for the discrepancy in numbers. This could be addressed by limiting the time period for this analysis to a period when all databases were available. However, this was not practical due to the relative dearth of temporal data within the available databases. If it had been practical, limiting the time period would also dramatically reduce the number of young people in my cohort. Moreover, it might tell me more about the databases and less about total ACE exposure in the population (as recorded in routinely-collected data). Another factor accounting for the discrepancy in numbers of people per database was the intrinsic nature of the databases. For example, most young people will have had contact with a GP, whereas a considerably smaller proportion of the population will have cause to interact with specialist services, such as social care (CINW, CRCS and LACW) or a substance misuse service (SMDS), and even fewer thankfully pass away in childhood (i.e. appear in the death registry, ADDE). To illustrate the difference in sample sizes across databases, Table 24 showed how many young people were present in each, irrespective of exposure to any ACEs. Table 24 (with its information on the demographic makeup of each database) can also be used in conjunction with the following findings to infer whether there was a sex skew inherent in the underlying database or if important differences exist in terms of sex by each ACE type.

Table 27 shows the number and proportion of ACE-exposed young people per database and Figure 19 illustrates these results graphically. The top three databases with the highest proportion of young people exposed to any ACEs were the three social care databases. In descending order these were 'Looked After Child – Wales' (LACW), in which young people had to have the status of 'looked after' to be part of the database (100% of LACW database; n=13,124), 'Child in Need – Wales' (CINW) (95.5% of CINW; n=30,009) and 'Children Receiving Care and Support' (CRCS) (93.5% of CRCS; n=24,353). Of note, a small proportion of young people were part of CINW or CRCS due to the child having a disability (requiring a care and support package from the local authority) or due to the parent having a physical disability (neither of which were part of my definition of ACEs), accounting for why these databases

were not also 100%, as with the LACW database. The remaining databases had much smaller proportional representation of young people who had experienced at least one ACE. However, the size of each database varied, as noted previously. Thus, the proportion may be low but the number of people high, and vice versa.

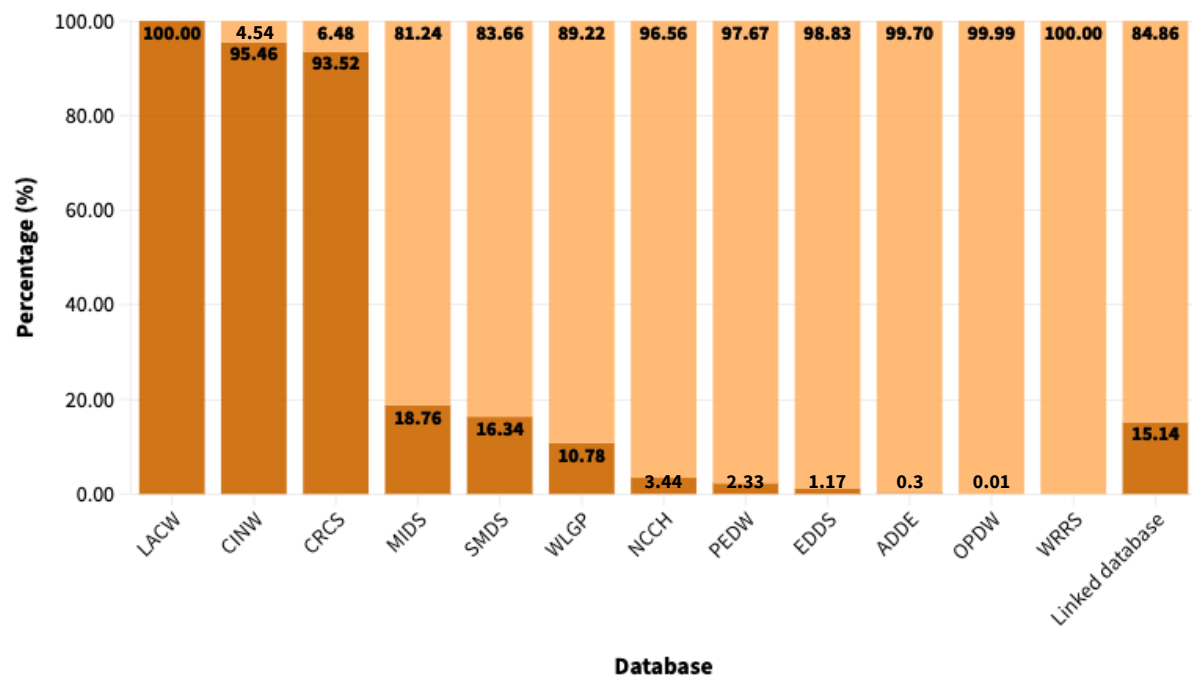
Table 27: Number of young people who experienced at least one ACE in each database

Database type	Database	Total number of young people who experienced ≥1 ACE per database	As a % of that database*	As a % of baseline cohort**
Demographics	WDSD	N/A	N/A	N/A
	ADDE	7	0.30	<0.001
Social Care	CINW	30,009	95.46	2.69
	CRCS	24,353	93.52	2.19
	LACW	13,124	100	1.18
Healthcare (General Practice)	WLGP	102,090	10.78	9.17
Community Healthcare	NCCH	9,007	3.44	0.81
	MIDS	32,484	18.76	2.92
	OPDW	34	0.005	>0.003
	WRRS	0	0	0
	SMDS	1,512	16.34	0.14
Acute Healthcare	PEDW	14,617	2.33	1.31
	EDDS	8,287	1.17	0.74
Combined	Linked Database	168,660	15.14	15.14

* The database totals shown in the last column of Table 24 were used as the denominators for the % calculations in this column. For example, 7 young people had a recorded experience of at least 1 ACE in the ADDE, a database with 2,372 individuals. Thus, this equates to 0.30% of the ADDE database.

** The baseline cohort of young people was 1,113,776, formed from the demographic database (WDSD) to which all other databases were linked. 1,113,776 was used as the denominator for the % calculation in this column. For example, 102,090 young people had a recorded experience of at least 1 ACE in the WLGP database; out of a cohort of 1,113,776, that is 9.17% of the baseline cohort.

Figure 19: Proportion of ACEs per single-agency database (in descending order), with the total proportion in the linked database (last bar)



ACE exposure status: ■ Percentage of young people exposed to ≥ 1 ACE ■ Percentage of young people exposed to 0 ACEs

LACW = Looked After Children – Wales; **CINW** = Child In Need – Wales; **CRCS** = Children Receiving Care and Support; **MIDS** = Maternal Indicators Dataset; **SMDS** = Substance Misuse Dataset; **WLGP** = Welsh Longitudinal General Practice; **NCCH** = National Community Child Health; **PEDW** = Patient Episode Dataset – Wales; **EDDS** = Emergency Department Dataset; **ADDE** = Annual District Death Extract; **OPDW** = NHS Hospital Outpatients Dataset – Wales; **WRRS** = Wales Results Reporting Service

Credit: created with flourish.studio (<https://flourish.studio>).

It was not possible to even attempt to measure ACEs in certain databases (i.e. no variables in these databases mapped to any ACEs included in this thesis's definition). As they did not contribute to the measurement of ACEs, these databases are omitted from subsequent tables and figures in this section.

These databases were:

- Demographics:
 - Welsh Demographic Service Dataset (WDSD)
 - Annual District Birth Extract (ADBE)
- Education:
 - Pre-16 Education Attainment and Attendance – Wales (EDUW)
- Community Healthcare:
 - Outpatient Referrals from Primary Care Dataset (OPRD)
 - NHS 111 Call Data (NHSO)
- Acute Healthcare:
 - Critical Care Dataset (CCDS)

Turning to the databases in which ACEs were measurable, Table 28 shows the number and proportion of young people recorded as experiencing each ACE per database. This highlights that a large number of young people (n=86,177) were known to have experienced 'other maltreatment' in the GP database (WLGP), representing 9.1% of the whole database. The maternal indicators database (MIDS) had records of 32,484 infants having a mother with current or previous experiences of mental health problems, representing 18.76% of this database. As such, the MIDS contributes significantly to my efforts to measure the ACE of parental mental health problems, with the large caveat that this database is limited to mothers only. The information in Table 28 could be used by individual professionals, practices and commissioners to understand which organisations are best at capturing certain ACEs and where gaps may lie, for example, to enhance routine practice and enquiry into childhood adversity. It could also be used by researchers if they are interested in a particular ACE or ACEs to guide which databases to focus on.

Table 28: Number and proportion (%) of young people per database exposed to each type of ACE

		Database											
		Demographics	Social Care			Healthcare							
		ADDE	CINW	CRCS	LACW	WLGP	NCCH	MIDS	OPDW	SMDS	PEDW	EDDS	WRRS
ACE type	Neglect	0 (0)	17,547 (55.82)	13,277 (51.00)	389 (2.96)	1,473 (0.16)	–	–	0 (0)	–	960 (0.15)	0 (0)	0 (0)
	Physical maltreatment	7 (0.30)	13,362 (42.51)	9,733 (37.38)	–	10,623 (1.12)	–	–	30 (<0.01)	–	9,209 (1.47)	8,264 (1.16)	0 (0)
	Psychological maltreatment	0 (0)	–	2,960 (11.37)	–	2,510 (0.27)	–	–	0 (0)	–	443 (0.07)	0 (0)	0 (0)
	Sexual maltreatment	0 (0)	–	436 (1.67)	–	5,553 (0.59)	1,154 (0.44)	–	0 (0)	–	666 (0.11)	0 (0)	0 (0)
	Financial maltreatment	–	–	<5 (<0.02)	–	0 (0)	–	–	–	–	–	–	0 (0)
	Other maltreatment	0 (0)	26,599 (84.62)	21,835 (83.85)	13,124 (100)	86,177 (9.10)	7,915 (3.02)	–	<5 (<0.01)	–	3,835 (0.61)	25 (<0.01)	0 (0)
	Parent or guardian mental health problems	–	11,793 (37.52)	11,384 (43.72)	–	–	–	32,484 (18.76)	–	–	–	–	–
	Parent or guardian substance misuse	0 (0)	11,553 (36.75)	8,736 (33.55)	–	–	–	–	0 (0)	–	1,426 (0.23)	0 (0)	–
	Parent or guardian is a victim of IPV	–	13,362 (42.51)	9,353 (35.92)	–	3,615 (0.38)	–	–	–	–	–	–	0 (0)
	Homelessness or unstable housing	–	56 (0.18)	52 (0.20)	119 (0.91)	–	–	–	–	1,512 (16.34)	–	–	–
	Involvement with CPS or living in care	0 (0)	7,151 (22.75)	7,591 (29.15)	13,124 (100)	16,557 (1.75)	3,780 (1.44)	–	<5 (<0.01)	–	172 (0.03)	0 (0)	0 (0)

Note to the reader: Each cell contains the number of young people exposed to each type of ACE, followed by the percentage in brackets (%) of young people that this represents in that database. For example, 16,557 of the 946,753 young people in the GP database had a record of living in care, and this represented 1.75% of the people in the GP database. Each database total, which was used as the denominator in the % calculations above, can be found in the last column of Table 24. The columns in the table above (Table 28) are not additive to get the ACE total per database because some young people will have experienced multiple ACEs; instead use Table 27 for ACE totals per database.

– = Where it was not theoretically possible to measure a specific ACE in that database e.g. there were no Read codes associated with ‘parent or guardian substance misuse’ so WRRS and WLGP have a ‘–’. However, if it was theoretically possible to measure (i.e. a Read code or ICD-10 code relates to this ACE) but there were no cases in a database, a 0 was given. For example, Read codes exist for ‘parent or guardian is a victim of interpersonal violence (IPV)’ but no cases were captured in WRRS.

IPV = interpersonal violence; CPS = child protective services

With regard to the most common types of ACE by database, ‘other maltreatment’ was the most common category of ACE in five of the twelve databases, namely LACW, CINW, CRCS, WLGP, and NCCH. ‘Physical maltreatment’ was the most common ACE in four of the twelve, namely PEDW, EDDS, ADDE, and OPDW. ‘Parent or guardian mental health problems’ was the only measurable ACE in the maternal indicators database (MIDS), and thus the most common ACE. Similarly, ‘homelessness or unstable housing’ was the only measurable ACE in the substance misuse database (SMDS), and thus most common. Finally, no ACEs were measurable in the blood test results database (WRRS) using these code lists. The number and percentage of young people exposed to the most common ACE per database are shown in Table 29.

Table 29: Most commonly recorded ACE per database

Database type	Database	Most common ACE per database	N exposed to most common ACE (% of that database)*
Demographic	WDSD	N/A	N/A
	ADDE	Physical maltreatment	7 (0.3)
Social Care	CINW	Other maltreatment	26,599 (84.6)
	CRCS	Other maltreatment	21,835 (83.8)
	LACW	Other maltreatment	13,124 (100)
Healthcare (General Practice)	WLGP	Other maltreatment	86,177 (9.1)
Community Healthcare	NCCH	Other maltreatment	7,915 (3.0)
	MIDS	Parent or guardian mental health problems	32,484 (18.8)
	OPDW	Physical maltreatment	30 (0.005)
	WRRS	—	0 (0)
	SMDS	Homelessness or unstable housing	1,512 (16.3)
Acute Healthcare	PEDW	Physical maltreatment	9,209 (1.5)
	EDDS	Physical maltreatment	8,264 (1.2)

* The database totals shown in the last column of Table 24 were used as the denominators for these % calculations. As an example of how the results above were calculated, the ADDE database had 7 young people recorded as experiencing that database’s most common ACE – ‘physical maltreatment’; in a database with an overall size of 2,372 people, this means 0.3% of the ADDE had experienced the most commonly recorded ACE within that database.

5.6.3.3 Data linkage

This section focuses on what can be learnt about the value of data linkage for the measurement of ACEs, compared to measurement in single agency data alone. By exploring the prevalence of each ACE in individual databases, it was possible to understand the contribution of each database alone. As shown previously (Table 27), the single database with the largest number of young people to have a recorded ACE was the GP database (WLGP), with 102,090 people experiencing at least one ACE (10.8% of the database itself, and 9.2% of this study's baseline cohort). The single database with the largest proportion (rather than number) of young people to have experienced an ACE was the looked after child database (LACW), of which 100% were classed as experiencing an ACE (n=13,124, so just 1.2% of the baseline cohort).

However, by linking together the 12 databases in which ACEs were measurable, this provided insights into whether linked data adds value when measuring the prevalence of ACEs in Wales. When the 7 healthcare, 3 social care and 2 demographic databases were linked together, the coverage of young people increased, with ACEs being identified in 15.14% (n=168,660) of the population. This was compared to 9.2% (or n=102,090) in the WLGP database, i.e. the single-agency database with the largest coverage of ACEs. This is illustrated in the last row of Table 27.

By linking these databases together, there was a 5.94% increase in the number of young people identified as experiencing at least one ACE; this was equivalent to an additional 66,570 young people being identified who were missed when using the single-agency GP data alone. In other words, just under two thirds (60.53%) of detected ACEs were identified in the GP data alone, but a further 39.47% were detected by linking data together.

5.6.3.4 Unmet need

This section focuses on what can be learnt about the unmet need of young people who experience ACEs. The analysis of the prevalence of ACEs per database (Table 28) allows early tentative exploration of where ACEs are being identified and recorded in the health and care system. This information could be used to infer where they are not, with the significant caveat that the same young people may not present to all services, so there may be no opportunity for a service to identify them.

In addition, the analysis of ACEs by sex (Table 26) provides a starting point to explore whether any services are more adept at identifying ACEs experienced by girls or boys; this could be done by triangulating ACE exposure by sex from other trusted data sources and seeing how this aligns.

However, as noted previously, the data does not allow for commentary on ACE exposure for people who are non-binary.

5.6.3.5 Prediction

Finally, this section focuses on what can be learnt to inform the prediction of mental health problems. When considering the aim of trying to predict mental health problems in young people, this analysis provided some avenues for further exploration. Depending on which ACEs are most predictive of developing a mental health problem (as highlighted through academic literature, clinical experience, and lived experience), it may be possible to develop early identification models using the relevant databases which best capture this ACE or ACEs (see Table 27 and Table 28 showing any ACE exposure by database, and each ACE type by database type, respectively). The information on ACEs could be used alongside information on other key risk factors for mental health problems, as highlighted in Chapter 4 (the Delphi framework of risk factors). The Timely team prototyped this type of process in social care data, demonstrated in a published technical report (Parkin et al., 2023) and journal article (Crowley et al., 2025).

5.7 Discussion

5.7.1 What was found

Using the SAIL Databank, and bringing together data from seven healthcare, three social care and two demographic databases, this study explored the feasibility of measuring adverse childhood experiences in routinely-collected data. Using routine data alone, the prevalence of ACEs experienced by young people aged 0 to 17 years in the Welsh population was recorded as 168,660 out of a population of 1,113,776 (or 15.14%). Interestingly, this was far less than was recorded in a national cross-sectional survey of adults in Wales in 2015, consisting of a sample of 2,028, where 47% of adults aged 18 to 69 reported experiencing at least one ACE (Bellis et al., 2015). There are a number of explanations for this discrepancy. For example, missingness in routinely-collected data is a problem; something may not routinely be asked about or recorded, or, if recorded, it may be in unstructured data only. Another explanation is that the present study in the SAIL Databank utilised a cohort of young people who were still in childhood, so could experience more ACEs as they age and it was not possible to limit the data by age to get a more comparable snapshot. In contrast, with the survey of Wales, the participating adults were recalling childhood experiences and were outside the exposure window for childhood adversity. In addition, the survey method collected data from individuals directly, whereas incidents of ACE exposure may not make it into routine records to be measurable. This could occur,

for example, if a person does not visit routine services, does not disclose an incident, is not asked about ACEs, or if a professional does not record the event when it is shared.

Secondary analysis of routine data and cross-sectional survey methods both have their own strengths and limitations. Unlike analysis of routine data, the survey method used by Bellis and colleagues (2015) is more liable to recall bias by the adults surveyed, as well as potentially self-report bias when interacting with a researcher as opposed to a clinician. Recall bias is particularly problematic with a sensitive topic such as childhood adversity (Hardt & Rutter, 2004; Tourangeau & Yan, 2007), and some researchers advocate for self-report methods during childhood instead to mitigate against this (Vink et al., 2019). In addition, though Bellis and colleagues (2015) strived for a nationally representative sample, selection bias remains an issue where participants can choose whether or not to participate (Althubaiti, 2016). However, secondary analysis of routine data like the present study in the SAIL Databank is still limited by who has access to routine services, what data are recorded, and whose records are successfully linked, all of which are open to bias and potentially missing the most vulnerable in society (Grath-Lone et al., 2021; Harron et al., 2017; Harron, Wade, Gilbert, Muller-Pebody, & Goldstein, 2014; Morgan et al., 2020). In addition, routine data suffer from another type of selection bias whereby people predominantly interact with services when experiencing problems (e.g. visit a GP when unwell but not whilst symptom-free, thus recorded contacts with young people are not at systematic intervals, nor are they at random) (McGee, Haneuse, Coull, Weisskopf, & Rotem, 2022). The implication of this for ACE measurement is that, rather than the 168,660 young people detected as experiencing at least one ACE being a representative sample of all young people exposed to ACEs, it is possibly more likely that these are young people who have more frequent interactions with health services. This is likely to be a two-way relationship whereby ACE exposure genuinely does mean young people experience more unwellness and healthcare interaction on average (as noted in the Introduction chapter), but also that instances of ACEs would be detected in these young people more even if this first relationship did not exist, because electronic health record data are being used for ACE measurement in the present study. One option to potentially improve the accuracy of the measurement of ACEs would be to weight the data using well-established results from other literature. However, weighting the results would be counter to the aims of the study – rather than claiming to be an accurate measure of the true prevalence of ACEs experienced by young people in Wales, this was intended as a feasibility study or proof-of-concept to understand the extent to which it is possible to use routinely-collected linked data for this purpose. Moreover, from a purely logistical perspective, the limited nature of the demographic information available in the SAIL Databank also precludes this endeavour as there is insufficient relevant information to robustly weight the results on. Finally, the

inability to limit the present cohort by age group to compare like-for-like exposure windows, or identify at what timepoint ACEs occurred, is a clear limitation of this work when considering the prevalence of ACEs. That said, routine data have a number of benefits for the purpose of measuring ACEs, including reducing the burden on young people and professionals, and possibly being more representative of the general population than research data (Wickersham & Downs, 2022). In addition, there was some precedent for using routinely-collected linked data for the measurement of ACEs, suggesting other researchers see it as a promising method too (Armfield et al., 2021; Sonesson et al., 2023; Syed et al., 2022).

Overall, regardless of data source, the most commonly recorded ACE in this cohort was ‘other maltreatment’, a composite category made up of types of maltreatment that did not clearly fit into a single category of psychological, sexual, physical, or financial abuse, nor neglect. This category included items such as those relating to ‘maltreatment histories’ or being the subject of child protective orders for unspecified reasons, as well as being considered at risk of harm. A significant number of young people – 110,256 (9.90%) – had experienced at least one recorded instance of ‘other maltreatment’. Interestingly, the second most prevalent ACE was just half as prevalent as ‘other maltreatment’; 52,385 (4.70%) had experienced ‘parent or guardian mental health problems’. Whilst this is proportionally much smaller, it remains a strikingly large number of young people experiencing this adversity, though may not be surprising considering around 1 in 4 adults will experience a mental health problem at some point during their lifetime (NHS England, 2024; Welsh Government, 2012). This number is more striking when the means of measurement is considered. With the data available to me, it was only possible to measure this ACE in the CINW, CRCS and MIDS databases. As such, this ACE is just being measured in young people who have contact with social care, where parental capacity is or has previously been affected by a mental health problem, or in infants where a health screening with their mother specifically identifies that she has current or past mental health needs. Thus, this large number of young people is just part of the picture and is only being captured when parent or guardian mental health problems are recorded in the child’s electronic records; an unknown number of young people also experience paternal mental health problems, or those of other close relatives or guardians, and many more young people are likely to experience familial mental health problems but not be in need of social care contact. One way to get closer to the true number of young people exposed to parental or guardian mental health problems would be to link parent or guardian data to that of children. Within SAIL, this could be done using residential ALFs in order to map a child’s household unit. Another team did this by linking maternal health records with children’s in the E-CHILD database, though again this limited the scope to focusing on mothers (Syed et al., 2022). This team

found that during the two years before and after birth, the period prevalence for maternal mental health problems was 22.2%, and the period prevalence for any of their 6 ACE domains (using 63 ACE indicators) was 39.1%. Other measurement methods could be used too, such as the national survey mentioned previously. In this survey of Wales, Bellis and colleagues found that 14% of adults had experienced parental mental health problems in their childhood (Bellis et al., 2015). The high prevalence of parent or guardian mental health problems in my analysis, as well as that noted in other studies, provides support for the idea of mitigating the impact of ACEs through familial or relational policies, i.e. working with the family as a unit, rather than viewing a child in isolation. This family unit idea is how social care operates and is also recommended by many in the field of child development (see for example, Cox & Paley, 2003; Harold & Sellers, 2018).

For comparison purposes, Table 30 presents the proportion of people exposed to each ACE type as measured in my study alongside the prevalence reported in two different surveys, summarised in a report by the Early Intervention Foundation (Asmussen, Fischer, Drayton, & McBride, 2020). The two surveys are: the national survey of over 2,000 Welsh adults mentioned previously (Bellis et al., 2015) and an NSPCC prevalence survey using a random probability sample of over 6,000 people (parents and children, young people and young adults in the UK) (Radford et al., 2011). These are not directly comparable findings to my own as Bellis and colleagues' (2015) survey included adults outside the exposure window, whereas my cohort were aged 0 to 17 years and still at risk for ACEs, and the NSPCC survey covered the UK, not just Wales. In addition, according to the Early Intervention Foundation (Asmussen et al., 2020), there were methodological differences between both prevalence surveys and the definition used for each ACE may have differed between the three approaches. However, this table gives a sense of the gap between detected and undetected cases of ACEs in the present study.

Table 30: Comparison of the prevalence of ACEs in the present study versus two other studies using survey methods

ACE prevalence as % of those included in study			
ACE type	SAIL database of routinely-collected linked data, Wales*	National survey of adults, Wales** (Bellis et al., 2015)	NSPCC prevalence survey, UK*** (Radford et al., 2011)
Physical maltreatment	4.0	17	8.4
Sexual maltreatment	0.7	10	1.0
Psychological or verbal maltreatment	0.5	23	7.0
Financial maltreatment	<0.001	Not measured	Not measured
Other maltreatment	9.9	Not measured	Not measured
Neglect	2.5	Not measured	16.0
Parent or guardian is a victim of interpersonal violence (IPV)	2.1	16	17.5
Parent or guardian mental health problems	4.7	14	17.0
Parent or guardian substance misuse	1.7 (combined alcohol and/or drug abuse)	14 (alcohol abuse); 5 (drug abuse)	2.3-19.0 (dependent use vs hazardous use respectively)
Involvement with child protective services (CPS) or living in care	2.3	Not measured	Not measured
Homelessness or unstable housing	0.2	Not measured	Not measured
Parental separation or divorce	Not measured	20	No reliable estimate
Parental imprisonment	Not measured	5	2.0
Any ACE type (i.e. ≥ 1 ACE)	15.14	47	Not reported

* Rounded to 1 decimal place to be more comparable with other columns.

** Data were aggregated to 0 decimal places in the report.

*** Decimal places included as shown in the report.

Evidently, measurement of ACEs in routinely-collected data alone is not sufficient to identify all young people exposed. There is clearly a large gap in the prevalence of ACEs identified within databases in SAIL, compared to other measurement methods such as national surveys of adults (Bellis et al., 2015). In future, it would be useful to combine approaches to understand whether there are differences in which types of young people are identified from each method (e.g. routine data use versus self-report in childhood; see for example, Vink et al., 2019). It may be that secondary analysis identifies the same young people as would already be detected through a self-report survey, but on the other hand, it could be that different young people are detected by the two approaches, meaning they could be used in a complementary manner to triangulate identification. Though clearly under-capturing ACE exposure, it is conceivable that secondary analysis of routine data still might add value in the endeavour of ACE detection because it provides a means of detecting ACEs in near real-time (as

opposed to waiting until later in childhood or adulthood to conduct surveys). This is especially important if early identification tools were deployed within clinical settings at the point of data collection. However, this would need careful consideration and testing as ACE exposure does not necessarily equate to poor mental health outcomes, and no intervention or watchful waiting may be more beneficial approaches in some scenarios where ACEs are identified.

Overall ACE prevalence patterns mask potentially interesting findings related to sex. In the present study, ACEs were detected more commonly in boys, with 89,166 boys (52.87%) experiencing at least one ACE, compared to 79,490 girls (47.13%), and 4 people of unknown sex (<0.00%). The baseline cohort database (the WDS) had slightly more boys than girls (50.74% boys; 49.26% girls; and <0.00% of unknown sex). Considering the 2021 census data for this age group in Wales, this sex skew aligns with the makeup of the general population (Office for National Statistics, 2022). In every one of the 12 databases used for this analysis, males were the predominant sex (see Table 24). However, this was most stark in the substance misuse database (SMDS), comprising 63.77% boys to 36.23% girls. More young boys were registered as deceased too, with 1,402 of the 2,372 (59.12%) recorded deaths in the death registry (ADDE) being boys. In contrast, the blood test results database (WRRS) and the GP database (WLGP) were the most sex-balanced, with 50.34% and 49.66%, and 50.62% and 49.38% boys to girls respectively.

The most heavily female-skewed adversity was ‘psychological maltreatment’, with 1 boy exposed for every 1.64 girls (2,179 boys and 3,571 girls; see Table 26). The most heavily male-skewed adversity was ‘homelessness or unstable housing’, with 1 girl exposed for every 1.78 boys (604 girls and 1,074 boys; see Table 26). These sex differences may reflect true exposure differences. However, they could also point to differences in identification or recording practices, for example, what questions are seen as salient to ask girls compared to boys, and what is recorded as noteworthy in each case. A further confounding factor in the ‘homelessness or unstable housing’ ACE in particular was that this was mainly identifiable in the substance misuse database, which was heavily skewed towards boys, in keeping with the relative proportion of boys who use substances compared to girls (lifetime risk odds ratio of 1:0.4 according to Kessler et al., 2005). The augmentation of results from surveys like the National Comorbidity Survey and research data like ALSPAC could help to tease apart whether these reflect true findings or are artefacts of the data sources.

In addition to understanding the prevalence of ACEs in the population, this study also sought to understand what, if any, additional value would be added by using multi-agency linked data compared

to single-agency data. It was found that the single database with the largest number of young people to have a recorded ACE exposure was the GP database (WLGP). 102,090 young people who had contact with a GP surgery were recorded as having experienced at least one ACE (10.8% of the database itself, and 9.2% of my baseline cohort). As such, if you wished to explore childhood adversity in a single database, GP data may be the best single source. Unfortunately, this comes with the large caveat that GP data are often held by single practices or consortiums, not in a single database, and to scrutinise it all, you would currently need a data sharing agreement with each individual practice, or consortium of GPs, which would be a huge undertaking. Progress on unifying GP data has been made though, after a large national team developed the OpenSAFELY platform (see for example, Andrews et al., 2022), facilitating analysis of GP data in England. However, at present OpenSAFELY only has ethical approval to be used for research relating to COVID-19 and has not been updated.

In the present study, compared to the 102,090 young people exposed to an ACE identified in the GP database alone, an additional 66,570 young people were identified as being exposed to at least one ACE when other community and acute healthcare, social care, and registry databases were linked together. That means just under two thirds (60.53%) of detected ACEs were identified in the GP data alone, but a further 39.47% were detected by linking data together. At a population-level, this difference in detection is a significant one. Moreover, different types of ACEs were better detected by different organisations (as shown in Table 28). Given the different trajectories associated with exposure to different types of ACEs (see for example, Agrawal et al., 2024; Anthony, Paine, Westlake, Lowthian, & Shelton, 2022), there is likely to be value in using linked data to measure different ACEs and understand more about the associated trajectories.

Finally, there were surprising findings about which databases did not contribute to ACE measurement (as shown in Table 23). In particular, it was especially surprising that no ACEs mapped to variables within the education database (EDUW), given that teachers are frequently on the frontline of detecting difficulties, for example in relation to mental health problems (stem4, 2019). This unexpected finding could be because the SAIL Databank only receives structured data, whereas ACEs may be found in unstructured data, such as notes recorded by teachers and school staff. It could also be as a result of the definition of ACEs used in this thesis (Chapter 3). For example, if the thesis had included poverty or young people's experience of physical disability as forms of childhood adversity, then variables within the education database would have been used (e.g. free school meal eligibility and Special Educational Needs and Disabilities (SEND) status, respectively). Though this database was not used in the present study for the measurement of ACEs, other risk factors for mental health

problems (as identified in the Delphi process in Chapter 4, and mapped in Appendix A.6: Section 9.1.6), would be found within the education data, including poverty and physical disability. Therefore, linkage of education data is still a priority for the Timely team which seeks to include a wide variety of risk factors for mental health problems, not just ACEs, into early identification models.

5.7.2 Strengths, limitations and challenges

This study has a great number of strengths. Firstly, the study consisted of a very large sample size, with a baseline cohort of over 1.1 million young people aged 0 to 17 years across Wales, which is far larger than many similar studies (Armfield et al., 2021; Downs et al., 2017; Syed et al., 2022), outside of Scandinavian contexts. Scandinavian countries have a more established tradition of research in large linked cohorts (Hesse, Thylstrup, Seid, & Skogen, 2020; Låftman, Modin, & Östberg, 2013; Tony Blair Institute for Global Change, 2024), facilitated in part by their citizens having unique identifiers used across databases. Alongside the cohort size, the representativeness of the sample was a considerable strength of this study; due to the SAIL Databank's underlying linkage method using GP registration as a proxy for inclusion in each project cohort, the cohort was near-whole-population. An estimated 98% of children in Great Britain are registered with an NHS GP (Saxena, Francis, & Sharland, 2012), suggesting this linkage method would yield good population coverage, though with the significant caveat that the young people who are not registered with a GP may be some of the most vulnerable. Only a very small proportion of the population have opted out of having their data included in the databank too (less than 0.025% of the population as of 2019), implying high representativeness in the data (K. H. Jones et al., 2019). Opt-out procedures can lead to bias because of which types of people are more likely to opt-out than others, but data from opt-out processes are generally more representative of the population than through opt-in procedures (de Man et al., 2023; Verheij, Curcin, Delaney, & McGilchrist, 2018).

The data available covered the population of young people across the whole of Wales over many years, increasing its utility for ACE measurement. Furthermore, to my knowledge, this study was the first to bring together and link data from these 12 databases, with the breadth of data helping to measure many cases of ACE exposure. By including data from different spheres of a young person's life, including community and acute healthcare, social services, and registrations of death, it was possible to better understand the utility of routinely-collected data for identifying young people who may be at a greater risk for developing mental health problems.

An additional strength is that much of the measurement of ACEs was based on validated code lists which had been approved by clinicians, thus increasing their robustness. The code lists I developed myself were not validated, which is a weakness of the study. However, the systematic approach taken to develop them ensured they were as robust as possible. Specifically, I was careful to be methodical in my approach to scrutinising all possible variables, working systematically through every variable description in the metadata of each of the available databases. This combination of using validated codes from the ADP combined with my systematically developed codes should enhance the robustness of the methods and add a level of credibility to the findings. Moreover, the data source used, SAIL, has a well-established reputation as being a world-leading source of robust linked data, and has led to over 700 publications to date providing insights into population health and functioning⁶.

Finally, a major finding and strength of the study was the fact that it was even possible to achieve the study aims; it was indeed feasible to use routinely-collected data to measure childhood adversity. This study was ambitious in the range of ACEs and also the breadth of databases used for this aim. Previous studies have achieved this in a more limited range of databases (see for example, Syed et al., 2022), or focusing on fewer ACEs (John et al., in press; John et al., 2023; Lowthian et al., 2021). However, young people interact with a number of routine services, including community healthcare and general practice, acute healthcare, social care, and the education system. In particular, the inclusion of social care data was an uncommon addition, due to the challenge of linking data without NHS numbers. Yet, this addition provided helpful insights into a population of young people with often the most severe exposure to ACEs. By attempting to measure ACEs in 18 different databases (see Table 22), and finding it was possible in 12 (see Table 28), more areas of a young person's life were covered, hopefully getting closer to the true prevalence of ACEs. Moreover, unlike other studies, this study utilised routine data for ACE measurement, rather than more highly curated research data (see for example, Houtepen, Heron, Suderman, Tilling, & Howe, 2018). This added immense complexity, but is likely to be more reflective of the general population. Moreover, it was more reflective of the data available to professionals making decisions about young people's support needs, and the data that are more likely to be used in any clinically valuable risk prediction tools.

Alongside the study strengths, there were a number of limitations. Firstly, though the sample was quite representative of the whole population of Wales, the results may not be representative of the UK as a whole, or of ACE exposure internationally. For example, in an online survey of 1,000 participants using a stratified sampling method in Seoul, South Korea, verbal abuse was the most

⁶ <https://saildatabank.com/data/publications/>

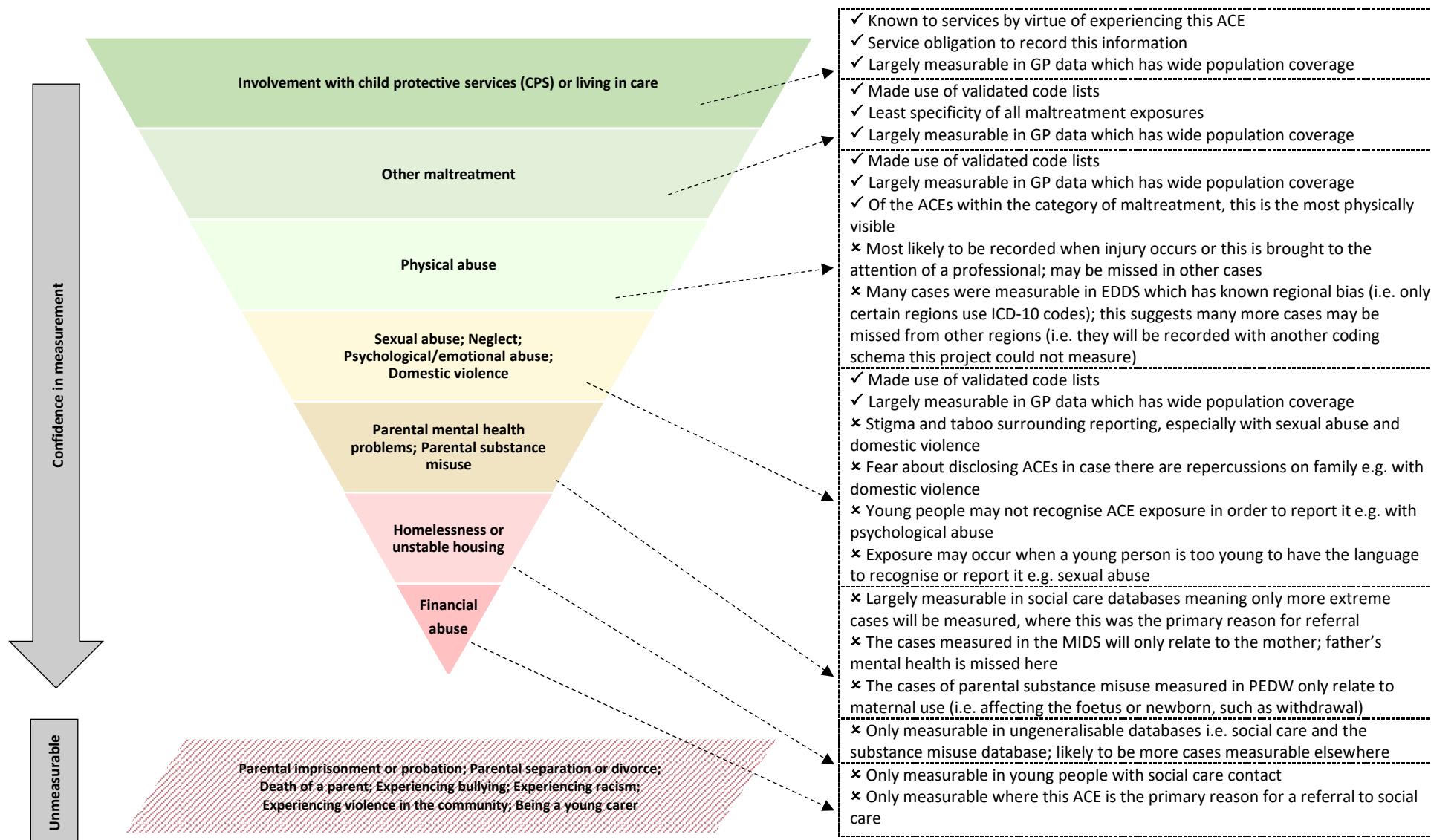
commonly reported ACE, whereas parental mental health problems were relatively less commonly reported (Son, Jang, Hong, Park, & Choi, 2024). In addition to lack of generalisability, there were also limitations of the databases used. As illustrated in Figure 15, each database had different temporal coverage, so the cohort would not have had data from all databases for the entire duration of ACE measurement, meaning ACEs may have occurred without being captured in the present measurement. Furthermore, during the scoping phase of this project, I selected the databases that appeared relevant for ACE measurement and young people's mental health, but the SAIL Databank has many more databases which were not utilised for this project and could potentially have captured cases of ACEs. That said, selecting only databases that appeared potentially relevant is in keeping with the Information Commissioner's Office (ICO) principles of using data which is adequate, relevant, and limited only to what is necessary for a task (Information Commissioner's Office, 2023), and this project was still data-rich. Though the SAIL Databank does not use identifiable data, the ICO's principles are still a useful guiding framework when working with pseudonymised data which is sensitive such as that used here, and balancing data minimisation with adequacy was an important endeavour. A further database issue was that the thresholds for including individuals may have changed over time, and this was a known issue with the child in need (CINW) and children receiving care and support (CRCS) databases, whereby the variables in both databases were the same but the legal definition for these children's eligibility for care changed slightly, so different groups of children might have been in one database and not the other. Moreover, each of the databases had quirks, for example, the CINW and CRCS were both censuses (i.e. snapshots) and a child would only be included in the census if they received care or support for the whole period between 1st January and 31st March in the census return year, otherwise they would be missed (Lee et al., 2022). Furthermore, because data linkage for these two databases relied on Unique Pupil Numbers (UPNs), records for most children were not available in those specific databases until the age of 3 when they have a UPN (Lee et al., 2022). The specific nuances and caveats of each of the 18 databases are detailed in Appendix B.1 (Table 57). There were also data quality issues, especially relating to there being unknown missingness in the databases, and it being likely that missingness was not at random with respect to ACE measurement (Doidge, Edwards, Higgins, & Segal, 2017).

This study also presented a number of challenges and the value of data linkage is pitted against a number of limitations. Firstly, logistically it is incredibly challenging to bring together data from multiple organisations and house this securely and pseudonymously. Data safe havens such as the SAIL Databank exist to allow this work but the time, money, expertise, and infrastructure associated with setting up and maintaining such trusted research environments (TREs) should not be

underestimated. Nor should the challenge of working with this data. For this project specifically, the relative lack of temporal data on anything other than ICD-10 and Read code events meant it was not possible to explore ACEs at different points in time. It would have been useful, for example, to be able to explore the prevalence of ACEs annually to understand trends, and to account for the fact that children age, and more years alive results in more opportunity for exposure to ACEs. Annual presentation would also help mitigate against the fact that some databases had existed or been available in the SAIL Databank for less time than others, meaning that fewer ACEs were likely to be recorded in them compared to long-standing databases. With the limited temporal data, the results present more of a snapshot of ACEs, using all data available, in order to get as close to the 'true' prevalence of ACEs as possible, but being mindful that this is likely to represent an underestimate for a number of reasons, including lack of service contact, database coverage and poor recording, amongst others (Verheij et al., 2018; Wickersham & Downs, 2022).

The sensitive topic of childhood adversity specifically also presents a number of challenges which play out in routine data, but are by no means limited to this data source. Many ACEs are associated with a feeling of shame or stigma, meaning they may go unreported, and professionals can find it challenging to raise the topic (Read, Hammersley, & Rudegeair, 2007). Their personal nature and a sense of social desirability may mean ACEs go undisclosed. In addition, young people may not conceptualise an experience as an ACE or trauma so may not report events. This could be because it does not feel significant or impactful to a young person, but could also occur in cases of traumatic events which children are too young to have the vocabulary for, especially in relation to more taboo subjects such as sexual abuse (Jackson, Newall, & Backett-Milburn, 2015; NSPCC, 2024). This presents a challenge – are results reflective of an absence of the exposure, or an absence of reporting (or more likely, some mixture of the two)? It is likely that all measured prevalences are underestimates and only reflective of what was recorded in routine sources; exposure to each ACE is likely to be much higher, as indicated by comparison with other measurement sources, such as in Table 30. However, some ACE types were likely to be recorded more comprehensively than others so there will be a smaller range of uncertainty. For example, involvement with CPS or living in care ought to be better recorded because there are service obligations to document this and liaise with other services. In contrast, recording of sexual abuse is likely to be less accurate (e.g. due to exposure before a child has the language to describe the event, reduced disclosure relating to stigma, professionals' hesitancy to enquire etc). Figure 20 gives an approximation of my varying levels of confidence about the measurement of each ACE type, alongside reasons for this.

Figure 20: Diagram to represent my approximate degree of confidence in the measurement of each ACE type, with details of some reasons underlying the degree of confidence



A further limitation of the study is that electronic health record data cannot provide much clarity about the subjective experience of ACEs, nor their context. With the available structured data alone, it was not possible to tease apart multiple exposures versus multiple reports or recordings of the same exposure, instead resulting in a binary outcome of whether or not young people had experienced one or more ACE and the prevalence of different types of ACE. There is debate amongst academic and mental health professional communities about the value and limits of ACE counts or scores, with some arguing they incorrectly reduce all ACEs down to being equivalently harmful and others noting that a count still has value, for example, because experiencing threat in multiple areas of a person's life may be as or more harmful than repeated episodes of the same type of ACE by undermining one's sense of safety and security (Lacey & Minnis, 2020; Reidy et al., 2021). Moreover, information on important factors surrounding ACEs was lacking, such as the severity, duration, developmental timing, subjective or lived experience, perpetrator relationship, and access to social support or confidants. Psychological understandings of trauma suggest that the cognitive appraisal of an event is as important when trying to understand the impact on mental health i.e. what sense did a person make of an event, rather than the nature of the event itself (Ehlers & Clark, 2000). Linked routine data could be used to explore the relative risk of mental health problems following exposure to ACEs, but complementing with more qualitative data such as case studies, interviews, or focus groups would provide more richness about the felt sense of ACEs. This study sought to explore a count of ACEs based on the notion that ACE exposure in and of itself is important at a population-level. However, a count (or exposure) does not necessarily equate to impact. This is likely to be truer of typically 'milder' ACEs, such as parental separation or divorce, where a young person's subjective experience of the event, as well as the context surrounding it, is likely to be even more predictive of the impact on mental health (Harold & Sellers, 2018). Count alone may be more predictive for more 'extreme' ACEs which have a stronger association with poor mental health outcomes (K. Hughes, Lowey, Quigg, & Bellis, 2016; Negriff, 2020), but this hypothesis would need investigating. Regardless, it is likely that any prediction models would need to include other variables besides ACEs alone, and the Delphi framework of risk factors presented in Chapter 4 (and Appendix A.4: Figure 32) provides a starting point for this endeavour.

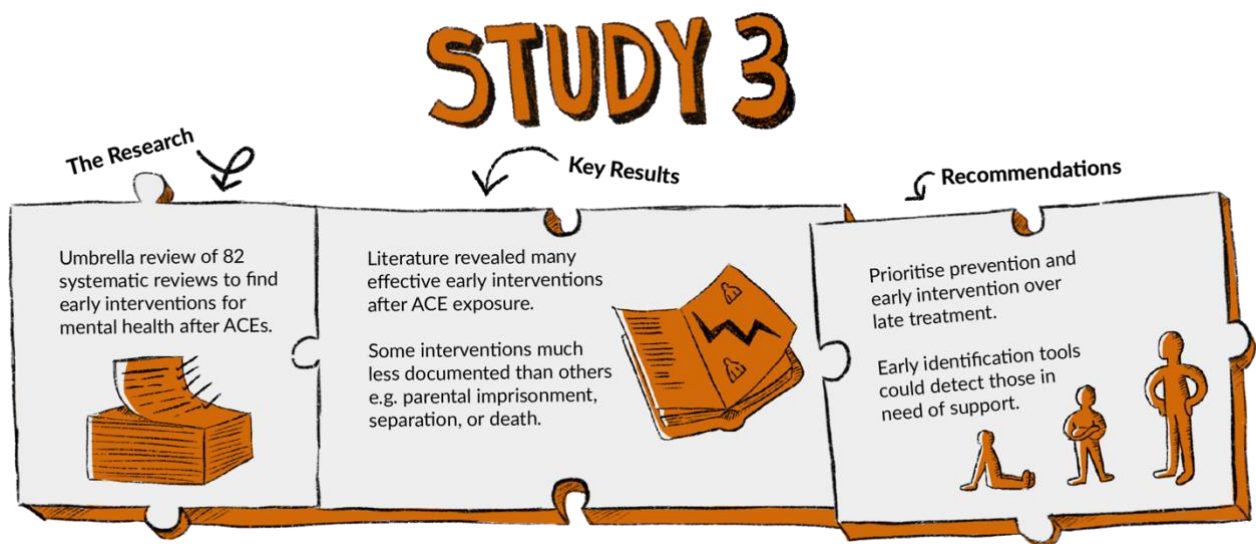
5.8 Conclusions

Electronic records provide a valuable and viable opportunity to measure some adversities experienced by young people during their development. However, this comes with the significant caveat that many instances of ACEs are likely to be missed in this detection method, so it should not be used in isolation. These exposures to adversity give important contextual information about young people's lives. Furthermore, routinely-collected linked data also have the potential to be used to understand

important outcomes for young people, including, but not limited to, mental health outcomes, physical health outcomes, educational attainment, employment opportunities, and criminal justice service interactions (see for example, Ann John et al., 2021). In spite of the benefits, the challenges and limitations associated with working with routine data should not be underestimated, nor should the value of collaborating with technical experts familiar with the data, or professionals and clinicians familiar with the data collection methods and context.

Accurate data for measuring ACEs robustly are crucial because they could be used to develop, implement and evaluate interventions to mitigate poor outcomes, as well as to understand more about multifinality (i.e. the different developmental trajectories after similar starting histories), and what factors determine whether or not a young person experiences poor outcomes following exposure to ACEs. This knowledge could be used to effectively target limited resources, be those from healthcare, social care, local authorities, or some combination.

6 Chapter 6: Umbrella Review Update of Prevention and Early Interventions for Mental Health Problems following ACEs



Credit: designed by Nifty Fox Creative, 2024.

6.1 Declaration of contributions

This umbrella review involved a huge and sustained team effort and could not have been carried out without the incredible support of a number of people. As such, everyone's contributions are detailed here; initials are included where appropriate as some individuals are referenced in the body of the chapter too. I (KP) designed the study and wrote the protocol and study materials (including data extraction sheets). Yi Zhang (YZ) created the screening decision chart, with advice from Dr Barry Coughlan, and with amendments made by me.

I conducted the literature search in 2021, with assistance from Yi, and advice from Dr Coughlan about converting search strategies between databases. Title and abstract screening was completed by Janelle Xiao (JX), Yi Zhang, Tara Ramsay-Patel (TRP), Emily Brewis (EB) and I. Full-text screening was completed by Emily Brewis, Charlotte Burdge (CB) and I; Emily and Charlotte carried out the majority of the full-text screening of >600 papers and I conducted reliability batches of >100. Data were extracted by Dihini Pilimalawwe (DP), Charlotte Burdge, Yi Zhang, Emily Brewis, Philippa Unthank (PU), Ava Berry (AB), Ella Denford (ED), Samantha Phippard (SP), Charlotte Tripp (CT), Emma Rengasamy (ER), Kate Evans (KE), Tara Ramsay-Patel and I. The risk of bias assessment was completed by Charlotte B, Tara, Eleanor Chatburn (EC) and I. Summary tables were produced by the data extraction team (including myself), but tidied and formatted by Tara, checked by me and reformatted or reproduced by me, as required. I produced additional results tables from tables produced by Tara, or created them independently where required. Dihini, Tara and I also created a conference poster for dissemination of early findings.

6.2 Acknowledgements

In addition to the incredible contributions of those mentioned above, I would also like to acknowledge the generosity of the teams who facilitated much of the person-power behind this review: Dr Robbie Duschinsky's Applied Social Science Group; the National Children's Bureau, and Dr Anna Moore's Timely team. These teams encouraged their students and staff to give time to this review, making the work possible.

Thanks also go to the EPPI reviewer team who allowed us to use their screening software as a team for free, and for providing guidance on this. Thank you to Eleanor Barker, Assistant Librarian at the University of Cambridge Medical Library, for helping me to initially develop a search strategy before it

became clear it would be better to ask if the Lester team (whose work we were updating) would consider sharing their incredibly thorough strategy for re-use.

So last but by no means least, this review was immeasurably helped by the generosity of Dr Sarah Lester and her team, especially Dr Theo Lorenc and Dr Claire Stansfield. They provided their comprehensive search strategies and RIS files for the papers they had included and excluded, as well as invaluable advice about how they had conducted their original review which the present work sought to update.

6.3 Chapter overview

The work in this chapter sought to understand what effective early interventions could be offered to young people if they could be identified earlier as at risk for mental health problems. It forms part of a theoretical care pathway of: 1) early identification (of risk factors like ACEs and possible risk of mental health problems) using routinely-collected data; then 2) early intervention to prevent or ameliorate mental health problems. Here, I present work on an umbrella review of prevention and early intervention strategies to support the mental health of young people who have experienced at least one ACE. A systematic review methodology was used and this work forms an update of a similar review carried out by an independent team.

6.4 Introduction

6.4.1 Rationale

Given the large body of research illustrating the link between exposure to ACEs and poor mental health outcomes, as described in the Introduction chapter of this thesis, I sought to understand what intervention options exist to mitigate potential poor outcomes. Prevention and early intervention for mental health problems were chosen as the focus, rather than treatment, given it is widely believed that earlier intervention is an important and promising area, especially for young people who have most of their life ahead of them, and many key upcoming milestones such as educational, social and identity-formation milestones (Children's Commissioner, 2023; Davey & McGorry, 2019; Early Intervention Foundation, 2018; Filkin et al., 2023; Mental Health Taskforce, 2016). If it is possible to identify young people exposed to ACEs earlier, using routinely-collected linked data, then it will be important to know what early interventions should be offered to support them. Before this can be offered though, it is essential to investigate whether intervention will lead to more benefit than any potential harms associated with intervening.

Many primary studies and systematic reviews already existed on this topic. As such, an umbrella review methodology was used, i.e. a systematic review of systematic reviews, to synthesise the existing evidence.

6.4.2 Important context to the review update

Whilst carrying out a practice search of grey literature, I found an umbrella review (Lorenz et al., 2020) which was similar to the present review, and upon contacting the authors found that this paper was part of a comprehensive review on the topic (Lester et al., 2019). Given the recency and comprehensive nature of their review, the present review became an update of the Lester team's work and I contacted their team to clarify points from their paper. We limited our searches to after the search date of the Lester team, but re-screened the papers Lester and colleagues had accepted in their review (n=98), as well as re-screening their papers which were excluded on 'Population' (n=1,853), 'Country' (n=39), and 'Language' (n=7) because our selection criteria differed here.

6.4.3 Background

Considerable amounts of literature, and in particular systematic reviews, exist which focus on prevention and early intervention strategies for individuals deemed to be at risk of poor mental health following ACEs. This chapter sought to bring this literature together by updating an umbrella review by Lester and colleagues (2019). The umbrella review approach draws on the methodological quality of systematic reviews, providing an overview of the various ways researchers have approached mental health intervention following ACEs. Umbrella reviews are considered to be an established method of locating, appraising and synthesising systematic reviews (Becker & Oxman, 2008).

Lester and colleagues (2019) reviewed 18 databases from 2007 to 2018 to identify systematic reviews of effectiveness data on people between ages 3 and 18 who experienced ACEs and received an intervention for this. They excluded any studies which they deemed to be less than 5.5 using the AMSTAR 2 quality appraisal rating, leading to a review of thirty-one systematic reviews. In the present umbrella review, I sought to update this pre-existing review in five ways:

- 1) Re-running the original search strategy for 2018 to present;
- 2) Extending the definition of young people to 0 to 25 years, thus including those younger than 3 years and older than 18 years;
- 3) Exploring additional research questions besides intervention effectiveness, for example, regarding barriers to implementation of interventions, intervention characteristics and unintended consequences of intervention;

- 4) Including relevant information from articles irrespective of their quality rating i.e. those which were originally screened out by Lester and colleagues (2019) due to the quality rating being below 5.5, as well as articles post-2018, as there could be valuable information on the more qualitative questions about implementation in these papers;
- 5) Running the search without 'English-language' limits in order to gain valuable information from international studies in the hope that this may in part support my aim of mitigating health inequalities in this work.

This update of the review strengthens the systematic evidence base on interventions for children and young people who have been exposed to ACEs by:

- 1) Synthesising the most up-to-date evidence from post-2018, which is likely to be important as research in the area of ACEs increases year on year (Nelson et al., 2020);
- 2) Incorporating data on what works for a broader definition of young people (0-25 years) which is more in keeping with the direction of travel for many youth services which are expanding their age coverage;
- 3) Drawing on insights from international research and reducing the bias associated with English-language limits.

This umbrella review sought to synthesise findings from systematic reviews and meta-analyses to explore the effectiveness of targeted/selective and indicated interventions (as opposed to universal interventions) for the mental health of children and young people exposed to ACEs. The review focused on interventions considered to be 'prevention' (i.e. before difficulties arose in an at-risk group) or 'early intervention' (i.e. as indicators of poor mental health started to emerge). It also explored barriers to implementing effective interventions given there is a wealth of research on interventions and yet negative impacts of ACEs persist as a public health issue today. Some suggested barriers to implementation of other interventions include small effect sizes leading to interventions not being widely adopted (e.g. depression interventions; NICE, 2013), poor investment due to short-termism in the thinking of governments and society at large (Bellis et al., 2019), loss of gains at follow-up (Stockings et al., 2016), issues with intervention fidelity, insufficient dose, lack of a clear metric for cost-effectiveness and issues with scalability (G. Allen, 2011). As well as barriers, the review also explored any adverse effects or unintended harm associated with intervention. For example, Stafford and colleagues found deterioration in 10% of people with at-risk mental state (ARMS) who had psychological treatment to prevent the onset of psychosis (Stafford, Jackson, Mayo-Wilson, Morrison, & Kendall, 2013). In addition, in their qualitative study of school-based mental health programmes,

Gronholm, Nye, and Michelson (2018) found that students experienced stigma from participation in interventions, which could act as a barrier to engagement in targeted mental health support. By identifying the implementation barriers and adverse effects specific to childhood interventions following ACEs, this review could help to inform possible solutions or ways to mitigate issues, as well as providing insights into when early interventions should and should not be offered. Finally, the review sought to extract information on cohort identification to help inform the development of predictive modelling tools for childhood mental health problems (i.e. by understanding how other studies have identified young people earlier).

6.4.4 Aims and research questions

The aim of this umbrella review was to provide an evidence synthesis of the effectiveness of targeted and indicated prevention and early intervention strategies for children and young people following ACEs. It also aimed to describe the characteristics of the interventions, including potential mechanisms behind intervention effects, as well as highlighting any barriers and enablers to implementation, and exploring unintended consequences or harms associated with the interventions.

To this end, this review sought to answer the following research questions for the years 2007 to 2021 (with a new search for 2018-2021 and revisiting relevant papers from 2007-2018):

Intervention characteristics:-

- 1) What prevention and early interventions are available to prevent or reduce poor mental health outcomes in children and young people who have experienced ACEs?
 - a) Is it possible to describe these interventions, including their intended setting, who provides them, the intended cohorts and target outcome (e.g. are they targeting prevention of specific conditions/diagnoses or general 'poor mental health outcomes')?
 - b) To what extent are different interventions targeted at or modified for different cohorts?
 - c) How are cohorts identified for study participation?

Intervention outcomes:-

- 2) Are these interventions effective?
 - a) For interventions identified as effective, what are the proposed mechanisms for their effectiveness?
 - b) For interventions identified as ineffective or harmful, what are the proposed reasons/mechanisms for this?

- c) Are there any risks or unintended consequences identified?
- d) How cost-effective are these interventions?

Intervention implementation:-

- 3) What helps and hinders implementation of interventions?
 - a) What are the identified barriers to implementation of interventions?
 - b) What are the identified enablers to implementation of interventions?

6.4.5 Outcomes of interest

Primary outcomes:-

- Effectiveness data (i.e. recorded qualitatively as effective/neutral/harmful and, where available, quantitatively as pooled effect scores);
- Intervention characteristics (e.g. modality, facilitators, intervention target, intervention modifications/tailoring for ACEs or subpopulations).

Secondary outcomes:-

- Method of cohort/participant identification (e.g. screening questionnaires, referral source etc);
- Barriers and enablers to intervention implementation;
- Mechanisms for intervention effectiveness/ineffectiveness/harmfulness;
- Cost-effectiveness data.

6.5 Methods

A systematic review methodology was used for the umbrella review, following guidance by Moher and colleagues (2009). Systematic reviews and meta-analyses were identified; these could be made up of primary studies with any study design (in order to gather all of the best available evidence on interventions for ACEs which may not lend themselves to traditional gold standard study designs like randomised controlled trials (RCTs)). The reviews were of prevention and early intervention studies which were aimed at children and young people, aged 0 to 25 years, who had experienced one or more ACEs from a pre-defined list (Table 31).

6.5.1 Protocol and registration

A protocol was developed and registered on PROSPERO (CRD: 42021252621; available from: https://www.crd.york.ac.uk/prospero/display_record.php?ID=CRD42021252621). This protocol followed the PRISMA-P guidelines for systematic reviews and meta-analyses (Moher et al., 2015; Shamseer, Moher, Clarke, Ghera, Liberati, Petticrew, Shekelle, Stewart, et al., 2015). The methodology

was also informed by the protocol of a similar umbrella review (Thomson, Bambra, McNamara, Huijts, & Todd, 2016) and systematic review (Soneson et al., 2019). Any deviations from this pre-defined protocol are detailed later in the Deviations from the Protocol section (Section 6.5.10).

6.5.2 Eligibility criteria

Table 31 briefly shows the inclusion criteria in PICOS format used for this review. More detailed inclusion and exclusion criteria are contained in Appendix C.1 (Table 59). Additional points of clarification which are important for reproducibility are also given in Appendix C.1.

Table 31: Study inclusion criteria

Item of PICOS	Criteria
Participants (P)	Children and young people aged 0-25 years; experienced ≥ 1 adverse childhood experiences (ACEs); considered at risk of or currently experiencing poor mental health outcomes. Included ACEs were: Physical abuse; Sexual abuse; Emotional abuse; Physical neglect; Emotional neglect; Domestic violence (either experiencing or witnessing); Parental or caregiver/guardian substance misuse (i.e. alcohol or drugs, including medication abuse); Parental or caregiver/guardian mental illness; Parental separation or divorce; Parental or caregiver/guardian death; Household member incarcerated or on probation; Unstable housing (i.e. homelessness, conflict-related displacement, involvement with child protective services (CPS) or living in care).
Intervention (I)	Targeted/selective or indicated interventions; preventative or early interventions for the benefit of children and young people who have experienced ACEs. The child or young person did not need to be the direct recipient of the intervention (e.g. their parent could be offered an intervention), but the young person's outcomes had to be reported. Interventions could be of any modality (e.g. psychological, behavioural, physical, pharmacological).
Comparator (C)	Not required but if included, would be children and young people who had experienced ≥ 1 ACEs and were offered another intervention, including waiting-list control, treatment-as-usual or other intervention.
Outcomes (O)	Effectiveness for mental health outcomes; no restriction on how this was defined by authors. Other outcomes were extracted too, but the focus of the review was mental health outcomes.
Setting (S)	No restriction.
Study design (S)	Systematic reviews and meta-analyses consisting of primary studies of any type.

6.5.3 Information sources and search strategy

Searches for this review were carried out on 9th July 2021 and 25th July 2021. Searches were carried out using search strategies shared by Dr Lester's team, of which the present review provides an independent update (Lester et al., 2019). Modifications to the searches were minimal and simply included correcting minor typos; altering for a different host site in one case; removing language limits; and adding a publication date limit to avoid overlapping with Lester's team's searches more than necessary. In order to identify relevant systematic reviews and meta-analyses, six databases were searched from their inception until July 2021 (host sites noted in parentheses): Applied Social Sciences Index and Abstracts (ASSIA; ProQuest); Cochrane Library (Wiley); Embase (Ovid); Medline (Ovid); NHS

Evidence (previously NICE; website now discontinued); and PsycINFO (EBSCOhost). Searches were tailored to each host site, but the same key terms were included in each search; MeSH terms were included where available.

Search terms covered three topics: (1) children and young people; (2) adverse childhood experiences, including specific ACEs as noted in definitions; and (3) interventions aimed at preventing poor mental health outcomes or intervening early to mitigate the mental health effects of ACEs. Between each of the three topics, the Boolean term “AND” was used and within each topic, the Boolean term “OR” was used. An example search strategy for Embase is included in Appendix C.2. To reduce possible bias, no language limits were applied. As mentioned earlier, publication date restrictions were applied (2018 onwards) to avoid overlapping with the Lester team more than necessary; some overlap was allowed to avoid missing any papers after their searches were run.

Database searching was complemented by the addition of grey literature sources such as unpublished PhD theses (using EThOS [e-theses online service; the British Library’s database of doctoral theses]; OATD [Open Access Theses and Dissertations]; and advanced Google searches), as well as hand-searching reference lists of included papers, and the addition of any articles which the review team were aware of from previous searches.

6.5.4 Study selection and data management

Five reviewers (KP, JX, YZ, TRP and EB) carried out title/abstract screening, starting with double-coding then moving to single-coding when appropriate. Inter-rater reliability was calculated using an online kappa score calculator (Scarpellini, 2020), with a pre-determined threshold set of ‘substantial agreement’ or above. At the title/abstract screening stage, EPPI-reviewer web (Beta) (Thomas et al., 2023) was used to identify and remove duplicate files (n=2,498), obtain abstracts of articles, and screen articles according to the inclusion and exclusion criteria. Additional detail is provided in Appendix C.1 (Section 9.3.1.2), describing how rigour was maintained in this process.

Titles/abstracts were screened in a hierarchical manner, with the earliest point of confident exclusion being cited as the exclusion reason. Exclusion points in order were: Publication Date (because of the re-screening process; to avoid duplicating/screening papers which were already captured in our search); Study Type; Population Type; Intervention Type; Evidence Type. This is illustrated in the decision flowchart in Figure 21. Disagreements on inclusion/exclusion were resolved by me.

After completion of the title/abstract screening, the included texts were downloaded into the reference manager Zotero v6.0.23 (Digital Scholar, 2023) in order to complete full-text screening. Four reviewers (EB, CB, YZ and KP) completed full-text screening, with an initial reliability batch being carried out to ensure inclusion/exclusion consistency. Cohen's kappa was again used to determine inter-rater reliability. Once sufficient reliability was reached, the remaining full texts were screened by a single rater. After reading the full text, if the article was relevant it was included for data extraction. If a rater was unclear from full-text screening, the article was discussed with me and/or included for data extraction in order to aid decision-making.

6.5.5 Data collection/extraction process

Data extraction was carried out by a team of thirteen researchers (KP, DP, CB, YZ, EB, PU, AB, ED, SP, CT, ER, KE and TRP), using a data extraction table in Google Sheets (Google, 2023) for basic study characteristics, and NVivo 12 (QSR International Pty Ltd, 2018) for all other study details, with data extracted into 'nodes' and 'child-nodes' relating to each element of the research questions. The extraction process was piloted with a training process to ensure consistency in data extraction. Further details of this process are in Appendix C.1 (Section 9.3.1.3).

6.5.6 Data items

Data items for extraction comprised those listed in Table 32. However, due to the nature of an umbrella review being a synthesis of already synthesised primary studies (in the form of systematic reviews), we anticipated that it would not be possible to extract information on all items for all papers, and that some items would become obsolete due to a dearth of information.

Table 32: Items for data extraction

Overarching item	Individual items
Basic paper information	• Inclusion/Exclusion • Short paper citation • Study aims • Number of primary studies included • Sample range • Study designs of primary sources
Participant characteristics	• Sex of participants • Age range (or average age) • Ethnicity (where stated) • ACE(s) experienced by participants • Any listed diagnoses • Other relevant characteristics
Intervention characteristics	• Modality of intervention • Prevention or early intervention • Modifications to intervention (e.g. to cater to specific populations, locations etc) • How the cohort was defined or identified (e.g. screening process, recruitment process) • ACE(/s) being targeted by the intervention • Setting, delivery mode (e.g. group, 1:1, in-person, telephone, online etc), deliverer • Intervention intensity (duration of each session, length of intervention) • Comparison group included (yes/no) • Follow-up time • Other intervention characteristics
Results	• Outcome measures used to test effectiveness (i.e. relating to young person's mental health, others' mental health, other outcomes) • Summary finding in terms of mental health outcomes (i.e. effective, ineffective, mixed, inconclusive) • Harms or unintended consequences of intervention • Cost-effectiveness (if reported) • Pooled effect size (if reported) • The 'voice' of the participants (e.g. any quotes from young people or comments on acceptability) • Other relevant results
Implementation	• Barriers and enablers to implementation • Mechanisms (either proposed by authors or tested) for effectiveness/ineffectiveness/neutrality
Miscellaneous	• Other important information • Additional references for consideration

6.5.7 Quality appraisal of individual studies

Systematic reviews and meta-analyses which were deemed relevant for inclusion in the review were critically assessed using a modified version of the AMSTAR 2 tool (Shea et al., 2017a) in order to rate their methodological quality (included in Appendix C.3). Critical appraisal was carried out by four researchers (KP, CB, TRP and EC), with an initial training period and double-coding to ensure consistency, after which papers were single-coded. Further details of this process are included in Appendix C.1 (Section 9.3.1.4).

All included papers from 2018-2021 were critically appraised, as well as any from the pre-2018 re-screened papers. For the papers which were included by the Lester team and also by our team, we did not re-appraise these but instead used the scores allocated by Lester and colleagues. To determine this was a legitimate approach, CB and I re-assessed a batch of five papers to ensure our ratings were sufficiently consistent with Lester and colleagues. Our pre-defined threshold for sufficient consistency was ± 2 points on the AMSTAR 2 tool. Papers rated by Lester and colleagues are indicated with an 'L' in the quality appraisal tables (in the Results section); those rated by our team are indicated with a 'P' (for 'Parkin's team').

6.5.8 Synthesis of results

Results were presented in a narrative synthesis, informed by similar studies and guidance from Popay and colleagues (2006), highlighting effective, harmful and neutral interventions, as well as intervention characteristics. Where there were data available, we also presented information on secondary outcomes i.e. mechanisms for effectiveness, barriers and enablers to intervention implementation, unintended consequences and cost-effectiveness information. Data were also synthesised into tables. The narrative synthesis and tabulated data inform research questions 1-3.

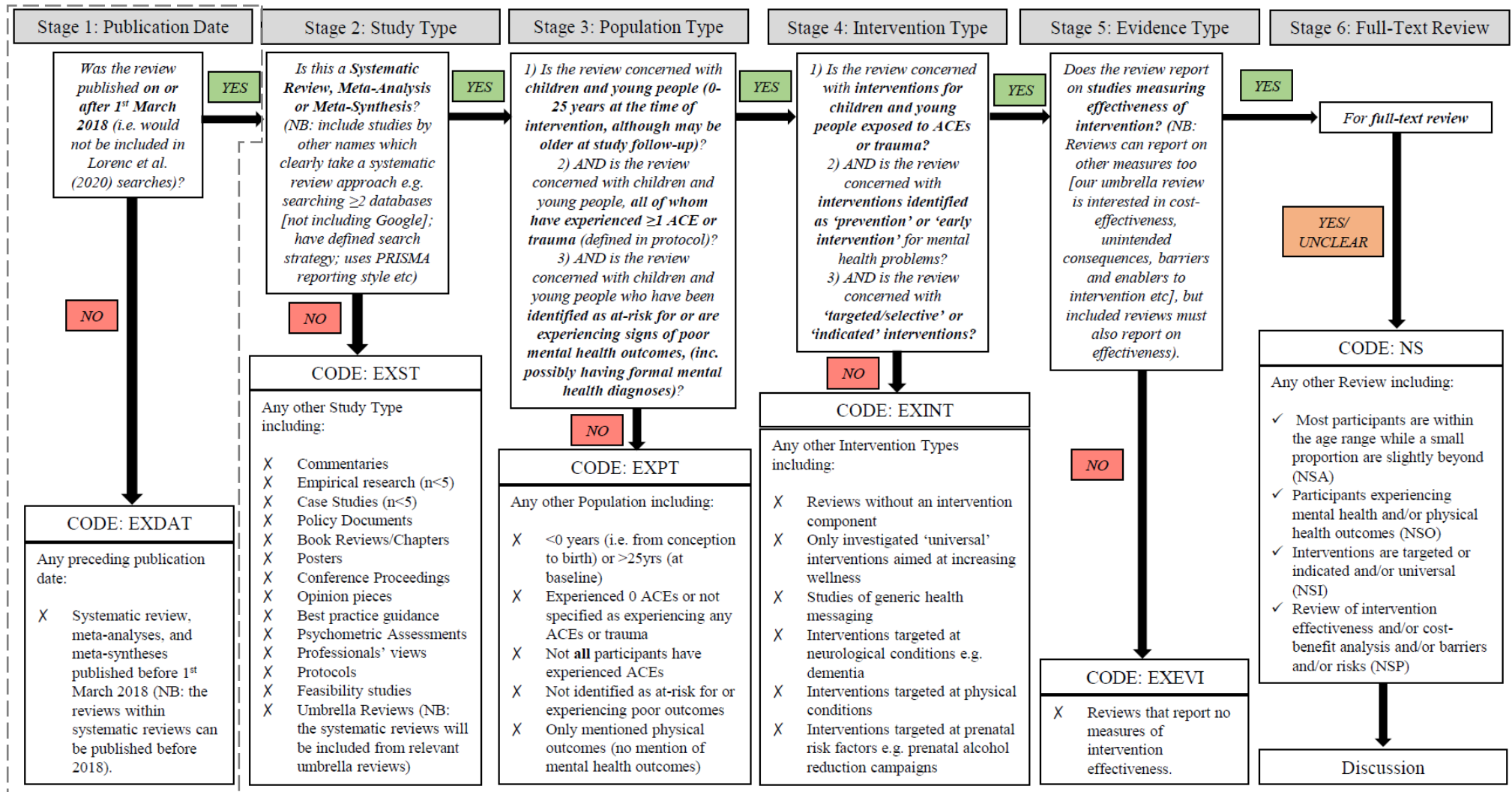
6.5.9 Ethical considerations

Being aware of the distress that could be caused by reading such material about ACEs, I set up a system of support for the team, details of which are provided in Appendix C.1 (Section 9.3.1.5).

6.5.10 Deviations from the protocol

The methods deviated from the registered protocol in the following ways, all of which are likely to enhance the review rather than detract from its robustness: 1) during searches, in addition to the five databases listed, we also searched NHS Evidence as we had usable search strategies readily available provided by the Lester team; 2) during title/abstract screening phase, we screened all items instead of stopping after reaching a saturation point (as initially intended), due to the prioritisation/text mining function in EPPI-reviewer web (Beta) not being correctly set up; 3) tools used: used NVivo software alongside Google Sheets for data extraction of all included papers.

Figure 21: Decision flowchart for screening



--- The dashed part of the screening process was only applied to the papers from 2018-2021 searches (i.e. not the re-screened papers from Lester and colleagues). This was to avoid screening papers in duplicate which would already be in the batch to be re-screened. In addition, all papers had to be published in 2007 or later i.e. so no papers were included prior to those in Lester and colleagues' work.

6.6 Results

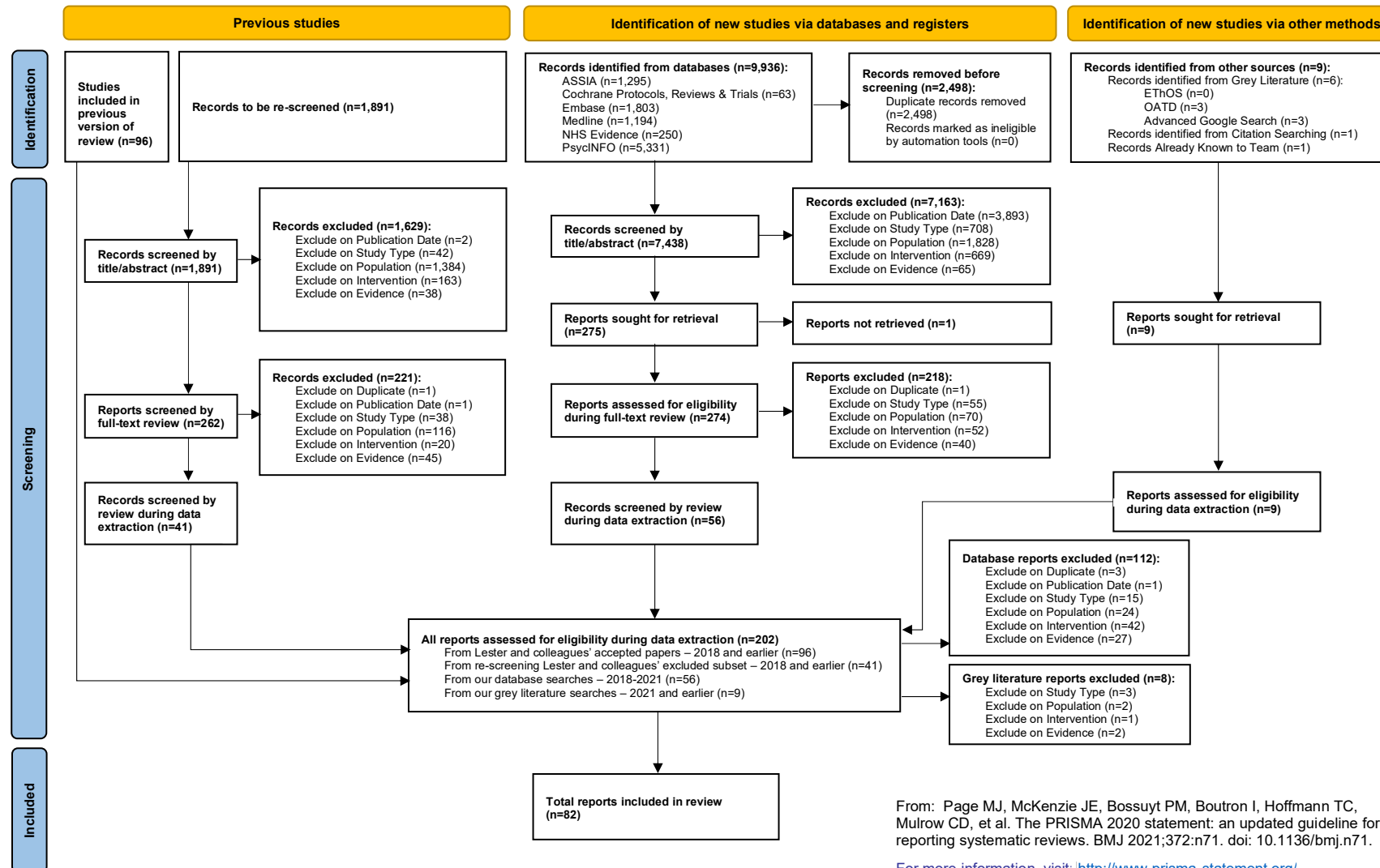
The results of the literature searches and screening process are shown in the PRISMA flowchart in Figure 22. A total of 11,827 texts were identified, of which 9,936 were found by running database searches and 1,891 were from re-screening files excluded by the Lester team. After screening titles/abstracts, 641 full texts were retrieved and read. This resulted in review/data extraction of 202 papers, of which 82 met all inclusion criteria and were included in the final analysis. As an ad-hoc step to arrive at the 82 for final inclusion, I re-read all papers marked for inclusion or possible inclusion by the team and made the final decision on which papers were included; this additional quality assurance step was carried out due to the ambiguity around certain criteria such as the distinction between early intervention versus treatment. A list of the final 82 papers for inclusion can be found in Appendix C.5.

Study characteristics are described in the tables later in the text. They are presented in terms of the main ACE type (as implied by the source paper) in order to be needs-led and also to aid readability. However, ACEs commonly co-occur and many participants would have experienced more than one type of ACE, so this is a simplistic representation purely to help make sense of the results. Where they were known, additional ACEs experienced by participants are detailed in the tables too. Of note, 2 of the 82 papers were analysed in two parts (Bee et al., 2014; Howarth et al., 2016), with results taken from relevant sections of these papers. This was because these longer papers had chapters which covered different relevant samples so were akin to being two papers for the purposes of this review. Where this is the case, it is indicated in the results as follows: Howarth et al. (2016) – *chapters 3 & 5*; Howarth et al. (2016) – *chapter 7*; Bee et al. (2014) – *chapter 4*; Bee et al. (2014) – *chapter 5*.

The Results section is made up of two parts: the primary results i.e. relating to the primary research question on intervention effectiveness (Sections 6.6.2 to 6.6.2.4) and the secondary results (Sections 6.6.3 to 6.6.9). Within the primary results section, the 82 articles are grouped as follows, based on their main focus: 'Abuse and Neglect' (n=12); 'Household Adversity' (n=32); 'Involvement with Child Protective Services (CPS) or Living in Care' (n=28); and 'Unstable Housing' (n=10). Within these main groupings, the specific ACEs are described in greater granularity too; for example, the type of abuse or type of household adversity. After the primary results, the secondary results are presented, for example, on cohort identification, intervention modifications, implementation barriers and enablers, and so on.

6.6.1 Study selection

Figure 22: PRISMA flowchart



6.6.2 Results for primary research question

Table 33 provides a key and notation explanation for all of the results tables in the primary results section which follows.

Table 33: Key and notation explanation for results relating to the primary research question

Quality appraisal tables:

Raters:-

This shows which team carried out the quality appraisal. Possible values are:

- **L** = Lester's team
- **P** = Parkin's team (i.e. the present review team)

Question answers:-

Possible responses to the quality appraisal questions were as follows:

- **0** = no
- **0.5** = partial yes
- **1** = yes
- **X** = not applicable

Question total scoring:-

- ***** = questions marked with a single asterisk were not included in the final score by the Lester team (but were by our team); these were questions 3, 14 and 15.
- ****** = questions marked with a double asterisk were not included in the final score by the Lester team or our team; these were questions 11 and 12 and they were omitted as they were not relevant to the present review.
- **Score /14** = this is the total score when questions 11 and 12 were omitted and is the quality appraisal total score used in the present review.
- **Score /11** = the Lester team omitted questions 3, 11, 12, 14 and 15 from the total score in their review. As such, a score out of 11 is provided in addition to the score out of 14 to present comparable quality appraisal scoring as Lester and colleagues review paper.

Effectiveness summary tables:

Miscellaneous:-

- **NS** = not specified

Sample range:-

- **II** = this is the sample range of young people unless otherwise specified (e.g. in some cases it was the number of mothers but they may have had multiple children and this would not be known). Where possible, the sample range was calculated by taking the lowest and highest bound of the sample (control + intervention group for each e.g. if the study with the smallest sample had 5 in the intervention group and 5 in the control group, the lowest bound would be 10). If this was not possible to calculate, we used the sample range reported in the paper.

RAG (Red, Amber, Green) rating:-

This provides a crude summary of effectiveness in terms of childhood mental health outcomes specifically (not in terms of any other outcome). The summary is based on the conclusions of the original authors of the systematic review and the RAG rating is meant to be illustrative only. The rating should be used alongside the more detailed narrative summary of effectiveness, and for more nuanced detail, refer to the source papers.

- **Red box** = Not Effective
- **Amber box** = Mixed (i.e. evidence in favour and against effectiveness)
- **Green box** = Effective
- **Grey box** = Inconclusive (i.e. insufficient evidence or few primary studies available)

Study designs:-

- **RCT** = randomised controlled trial
- **NRCT** = non randomised controlled trial
- **CCT** = controlled clinical trial
- **CT** = controlled trial
- **NCT** = non controlled trial

Intervention types (where not individually specified):-

- **CBT** = cognitive behavioural therapy
- **T-CBT or TF-CBT** = trauma-focused cognitive behavioural therapy
- **CBT for PTSD** = cognitive behavioural therapy for post-traumatic stress disorder

6.6.2.1 *Results: Abuse and Neglect*

A total of 12 articles focused on types of abuse and neglect, and were grouped together based on this. Of these 12, the primary ACE for each was as follows:

- sexual abuse (n=2) (Herbert & Bromfield, 2016; Indrayani et al., 2020);
- witnessing or experiencing domestic violence (n=2) (Howarth et al., 2016; Rizo, Macy, Ermentrout, & Johns, 2011);
- physical abuse (n=1) (Montgomery, Gardner, Bjornstad, & Ramchandani, 2009);
- emotional abuse (n=1) (Schrader McMillan et al., 2008); and
- maltreatment (mixed) (n=6) (J. G. Fraser et al., 2013; Gutterswijk et al., 2020; Kanine, Tunno, Jackson, & O'Connor, 2015; Lindstrom Johnson, Elam, Rogers, & Hilley, 2018; Silverman et al., 2008; Waechter & Wekerle, 2015).

More specific information about the ACEs, any secondary ACEs and other participant characteristics are also detailed in Appendix C.4: Table 62. As shown in Table 34, these studies ranged in quality from 2 to 10.5 (out of 14) on the AMSTAR 2 quality appraisal tool; the median rating was 5. The 12 systematic reviews were made up of primary papers which utilised a variety of study designs, including those with and without randomisation, with and without control groups, and with and without follow-up points.

Interventions for abuse and neglect were highly varied, including a mixture of parenting interventions/skills training, psychological interventions (including psychoeducation and different modalities of psychotherapy), non-residential care, and 'Eastern Arts' such as mindfulness, as well as interventions described as multicomponent interventions. Some interventions were more like structural/organisational approaches or place-based interventions (e.g. multi-disciplinary teams such as Children's Advocacy Centres (CACs), therapeutic day treatment programmes, and residential care). Furthermore, some interventions specifically mentioned taking a 'trauma-informed' approach, either with children or parents.

Of note, the child was not necessarily the direct target of intervention; the intervention target could be the child, the parent, the parent-child dyad, and/or the family unit, all for the purpose of supporting the child's mental wellbeing. For example, parents were provided with parenting/skills training, therapy, counselling, or drug treatment where appropriate. The setting of interventions varied too, including homes, schools, treatment centres, and residential care settings.

On the whole, early interventions seemed to show promise for mitigating poor mental health outcomes in young people who experienced abuse and/or neglect, with results tending towards mixed or effective (but two studies suggesting inconclusive findings). For more details of study designs, intervention types and a summary of findings, see Table 35.

Table 34: Quality appraisal of studies (Abuse and Neglect)

	Reference	Raters	Question																Score /14	Score /11
			1	2	3*	4	5	6	7	8	9	10	11**	12**	13	14*	15*	16		
SA	Herbert & Bromfield (2016)	L	0	0	0	0.5	0	0	0	0.5	0	0	X	X	0	X	X	1	2	2
	Indrayani et al. (2020)	P	0	0	0	0.5	0	0	0.5	0	0	0	X	X	0	0	X	1	2	2
DV	Howarth et al. (2016)	L	1	1	0	0.5	1	1	1	1	1	0	1	0	1	1	0	1	10.5	9.5
	Rizo et al. (2011)	L	1	0	0	0.5	0	0	0	0.5	0	0	X	X	0	X	X	0	2	2
PA	Montgomery, Gardner & Bjornstad (2009)	L	1	0	1	1	0	0	0	0.5	0	1	X	X	1	X	X	0	5.5	4.5
EA	Schrader McMillan et al. (2008)	L	1	0	0	1	0	1	0.5	0.5	1	0	X	X	0	X	X	0	5	5
Maltreatment (mixed)	Goldman Fraser et al. (2013)	L	1	0	0	1	1	1	0	0.5	1	0	X	X	1	X	X	1	7.5	7.5
	Gutterswijk et al. (2020)	P	1	0	1	1	1	1	0.5	1	0.5	0	0	0	0	0	1	1	9	7
	Kanine et al. (2015)	L	1	0	0	0.5	0	1	0	0.5	1	0	X	X	1	X	X	0	5	5
	Lindstrom Johnson et al. (2018)	P	1	0	0	1	0	1	1	1	0	0	1	0	0	1	1	1	8	6
	Silverman et al. (2008)	L	1	0	0	0.5	1	0	0	0	1	0	1	0	0	0	0	0	3.5	3.5
	Waechter & Wekerle (2015)	P	1	0	1	1	0	0	0	1	0	0	X	X	0	1	X	0	5	3

SA = sexual abuse; DV = witnessing or experiencing domestic violence; PA = physical abuse; EA = emotional abuse

Table 35: Study characteristics and summary of findings (Abuse and Neglect)

Reference	Number of primary studies [N of articles]	Sample range	Study designs of primary studies	Summary finding for mental health outcomes (with intervention type/focus)	Effectiveness RAG rating
Sexual Abuse					
Herbert & Bromfield (2016)	27 [27]	NS	Mixed: 14 with a control group, 9 without a control group (including 3 qualitative studies)	Inconclusive (multi-disciplinary teams such as Children's Advocacy Centres [CACs], some of which include therapeutic services like CBT)	
Indrayani et al. (2020)	NS [12]	NS	NS	Effective (T-CBT or trauma-informed care)	
Domestic Violence					
Howarth et al. (2016) – chapters 3 & 5	13 [34]	66-258	Mixed: 9 RCTs and 4 CCTs (non-randomised controlled clinical trials)	Effective (CBT, parenting skills and advocacy, psychoeducation)	
Howarth et al. (2016) – chapter 7	19 [26]	1-194	Mixed: 1 study with a comparison group, the remainder had a pretest-posttest design	Effective (psychoeducation, psychotherapy, advocacy for mothers, guided self-help for mothers)	
Rizo et al. (2011)	NS [31]	22-223	Mixed: 7 pretest-posttest quasi-experiments, 11 non-experiment pretest-posttest design, 6 NRCTs, 2 experimental, 1 descriptive report of findings from a large demonstration project, 2 non-experimental, 1 modified group pretest-posttest design (dropouts were control), 1 did not specify design	Effective (counselling and therapy interventions); Effective (parenting interventions: Errorless Compliance Training); Effective (multicomponent intervention)	
Physical Abuse					
Montgomery, Gardner & Bjornstad (2009)	NS [14]	NS	Mixed: some RCTs, some not specified	Mixed (child-focused interventions); Effective (parent-focused interventions); Inconclusive (family-focused interventions)	
Emotional Abuse					
Schrader McMillan et al. (2008)	21 [26]	1-305 mothers	Mixed: 7 RCTs and 14 NRCTs	Effective (CBT for emotionally abusive parents); Mixed (parent-infant psychotherapy);	

				Mixed (drug treatment and CBT for emotionally abusive parents who abuse drugs)	
Maltreatment (mixed)					
Goldman Fraser et al. (2013)	17 [20]	14-700	Mixed: 16 RCTs and 1 NCT	Mixed results, mainly inconclusive (therapeutic interventions with maltreated children and parenting interventions for parents/carers of maltreated children)	
Gutterswijk et al. (2020)	24 [24]	NS (total = 16,943)	Mixed: 13 RCTs, 7 quasi-experimental matched, 4 quasi-experimental non-matched	Effective (non-residential, Treatment Foster Care Oregon for Adolescents [TFCO-A] more effective than home-based treatment programmes [HBT]); Ineffective (residential care)	
Kanine et al. (2015)	9 [9]	24-109	Mixed: 7 pretest-posttest designs, 2 follow-up studies, and 3 included comparison groups	Mixed (Therapeutic Day Treatment Programmes)	
Lindstrom Johnson et al. (2018)	21 [21]	21-203	Mixed: half RCTs and half with repeated measures pretest-posttest designs	Effective (several different trauma-informed parenting interventions)	
Silverman et al. (2008)	21 [21]	14-229 (of note, for early intervention sections [i.e. excluding treatment sections of paper], sample range was 46-198 and pooled sample size was 452)	RCTs	Mixed (psychosocial interventions including CBITS, Mental Health for Immigrants Programme, Resilient Peer Treatment)	
Waechter & Wekerle (2015)	8 [8]	55-500	Mixed: 6 RCTs, 2 pretest-posttest designs	Effective ('Eastern Arts' i.e., mindfulness meditation, yoga, tai chi, qigong)	

6.6.2.2 Results: Unstable Housing

A total of 10 articles focused on types of unstable housing and were grouped together based on this. Of these 10, the primary ACE for each was as follows:

- homelessness (n=6) (Altena, Brilleslijper-Kater, & Wolf, 2010; Bassuk, DeCandia, Tsertsvadze, & Richard, 2014; Coren, Hossain, Pardo Pardo, & Bakker, 2016; Morton, Kugley, Epstein, & Farrell, 2020; Noh, 2018; Slesnick, Dashora, Letcher, Erdem, & Serovich, 2009); and
- displacement and being a refugee (n=4) (Mitra & Hodes, 2019; O'Higgins, Ott, & Shea, 2018; Piegenschke, Sihorsch, & Christiansen, 2019; Williamson, Landis, Shannon, Gupta, & Gillespie, 2017).

More specific information about the ACEs, any secondary ACEs and other participant characteristics are also detailed in Appendix C.4: Table 63. As shown in Table 36, these studies ranged in quality from 2 to 12 (out of 14) on the AMSTAR 2 quality appraisal tool; the median rating was 7.25. When considered separately, homelessness studies had a median rating of 7, and displacement studies had a median of 8. The 10 systematic reviews on housing instability were made up of primary papers with various study designs. Despite the potentially challenging nature of conducting research in this particular area, methodological strategies to enhance rigour were employed in many cases, including randomisation, quasi-randomisation and control conditions. Furthermore, qualitative methodologies were used which could provide richer findings, for example, to help understand the actual experience of young people involved.

For details of study designs, intervention types and a summary of findings, see Table 37. Perhaps due to the challenge of reaching and/or maintaining contact with young people who experienced homelessness, displacement or refugee status, many of the interventions in this category notably seemed quite responsive, flexible or creative in nature, opportunistically delivering interventions to young people. These opportunistic and adaptable approaches may have been used for a number of reasons, including: out of necessity in unstable conflict settings; due to difficulty maintaining contact with young people with no fixed abode; and to overcome some young people's understandable wariness towards statutory services or authority figures (due to negative previous experiences). In some cases, this included briefer, more ad-hoc or outreach interventions (such as brief motivational interventions, drop-in centres, and outreach programmes). Moreover, a couple of these interventions included positive/strengths-based components rather than problem-focused interventions only, for example living/vocational skills, strengths-based psychological interventions, and creative outlets, like dance, yoga and active science sessions (Altena et al., 2010; Noh, 2018; Williamson et al., 2017).

In terms of effectiveness, from the rough RAG ratings shown in Table 37, it appeared that interventions for young people who had been displaced showed mixed, tending towards effective outcomes for mental health, whereas the studies of interventions for homeless young people seemed more mixed or inconclusive. However, on closer scrutiny, amid the mixed overall RAG score, there were still some interventions that appeared effective for the mental health of young people who were homeless or without a fixed abode, especially interventions which seemed more intensive or personalised (e.g. intensive mental health case management, foster placements, CBT, and individual counselling).

Of note, modifications or tailoring seemed helpful in certain cases. For example, O'Higgins and colleagues (2018) found that foster placement was somewhat effective for preventing or mitigating mental health problems in unaccompanied refugee minors (URMs), but this was to a higher degree if children were fostered with families with matched cultural backgrounds. Similarly, Mitra and Hodes (2019) found that foster placement with a family of the same ethnicity was more effective for the mental health outcomes of URMs. Furthermore, some interventions differentially benefited those from certain groups. For example, Morton and colleagues (2020) found that a Community Reinforcement Approach (CRA) was particularly effective for young people who identified as gay, lesbian or bisexual, with these individuals reporting greater reductions in depressive symptoms and drug use than other participants.

Finally, it is worth noting that though no improvement was seen in the mental health outcomes of young people in some systematic reviews in this section, other outcomes could be positively affected by intervention. For example, in the SHIFT Study, reported in Bassuk and colleagues' (2014) systematic review, children's severe behavioural and learning problems did not significantly improve, but their mothers' PTSD symptoms did improve. Similarly, young people may have experienced improvements in domains other than their mental health. Though not the focus of the present umbrella review, these other benefits are important to hold in mind alongside the findings about young people's mental health outcomes.

Table 36: Quality appraisal of studies (Unstable Housing)

	Reference	Raters	Question																Score /14	Score /11
			1	2	3*	4	5	6	7	8	9	10	11**	12**	13	14*	15*	16		
Homelessness	Altena, Brilleslijper-Kater & Wolf (2010)	L	1	0	0	0.5	1	0	0	1	1	0	X	X	1	X	X	1	6.5	6.5
	Bassuk et al. (2014)	L	1	1	0	0.5	1	1	0	1	1	0	X	X	1	X	X	0	7.5	7.5
	Coren et al. (2016)	L	1	1	0	1	1	1	1	1	1	1	1	0	1	1	0	1	12	11
	Morton et al. (2020)	P	1	0.5	1	1	1	1	0.5	1	0	0	X	X	0	0	X	1	8	7
	Noh (2018)	P	1	0	1	0.5	0	0	1	1	1	0	1	0	0	1	0	0	6.5	4.5
	Slesnick et al. (2009)	L	1	0	0	0.5	0	0	0	0.5	0	0	X	X	0	X	X	0	2	2
Displacement and Being a Refugee	Mitra & Hodes (2019)	P	1	0	0	1	1	0	1	1	0	0	X	X	0	0	X	0	5	5
	O'Higgins, Ott & Shea (2018)	P	1	0	1	1	1	0	0.5	0.5	1	0	0	1	1	1	0	1	9	7
	Piegenschke, Sihorsch & Christiansen (2019)	P	1	0	0	1	0	0	1	1	1	0	X	X	1	1	X	0	7	6
	Williamson et al. (2017)	P	0	1	0	1	1	1	1	1	1	0	X	X	1	0	X	1	9	9

Table 37: Study characteristics and summary of findings (Unstable Housing)

Reference	Number of primary studies [N of articles]	Sample range	Study designs of primary studies	Summary finding for mental health outcomes (with intervention type/focus)	Effectiveness RAG rating
Homelessness					
Altena, Brilleslijper-Kater & Wolf (2010)	11 [11]	28-285	Mixed: 5 RCTs, 5 quasi-experiments, and 1 uncontrolled pretest-posttest design	Effective (Project Passage; an intensive mental health case management programme); Mixed (effective and ineffective), depending on mental health outcome (Community Reinforcement Approach [CRA]; intervention based on CBT-components); Mixed (effective and ineffective), depending on mental health outcome (Group intervention - CBT); Ineffective (Social Enterprise Intervention [SEI]; intervention to promote living/vocational skills)	
Bassuk et al. (2014)	6 [7]	107-2,307 families	Mixed: 3 time-series studies, 1 RCT, 3 NRCTs/before-and-after studies	Effective (Young Mothers Programme); Effective (Transitional Housing Programme); Ineffective (SHIFT Study; providing emergency shelter and case management; transitional housing and case management; or permanent supportive housing)	
Coren et al. (2016)	13 [18]	32-805	Mixed: comparison group study design; all were randomised or quasi-randomised studies. RCTs, CCTs, controlled before-and-after trials (CBAs) and quasi-randomised trials. Regression discontinuity designs	Inconclusive (time-limited therapeutically-based programmes vs other comparison interventions like drop-in centres and case management)	
Morton et al. (2020)	53 [66]	15-1,322	Mixed: 22 randomised evaluations (with or without control arm), 13 quasi-experimental studies with comparison group, 17 pretest-posttest design with no comparison group	Effective (CBT); Effective (Community Reinforcement Approach [CRA]; was particularly effective with gay, lesbian and bisexual youths in reducing depressive symptoms);	

				Mixed (brief interventions, usually motivational interventions aimed at using brief contacts and education to encourage specific behaviours); Mixed (outreach programmes); Effective (individual counselling and treatment interventions)	
Noh (2018)	11 [NS]	15-285	Mixed: 7 RCTs, 4 NRCTs	Mixed (psychological interventions comprising: art therapy, CBT-based interventions, family therapy, motivational interviewing, and strengths-based interventions)	
Slesnick et al. (2009)	34 [32]	10-570	Mixed: service evaluations, intervention evaluations, qualitative research on young people's experiences	Mixed tending towards effective (homelessness interventions comprising: mix of drop-in shelters, psychological interventions, case management)	
<i>Displacement and being a refugee</i>					
Mitra & Hodes (2019)	12 [13]	122-582	Mixed: 8 cross-sectional, 2 longitudinal, 3 case studies	Ineffective (low support residential settings had negative impact on mental health vs higher support setting or control Dutch group); Effective (foster placement with family of same ethnicity more effective for mental health outcomes than placement with American family); Effective (CBT for PTSD)	
O'Higgins, Ott & Shea (2018)	10 [9]	78-582	Observational	Effective to smaller degree (foster care placement for unaccompanied refugee children); Effective to high degree (foster care with matched cultural background)	
Piegenschke, Sihorsch & Christiansen (2019)	5 [6]	26-237	Mixed: RCT and NRCT	Effective (psychological interventions involving family members)	
Williamson et al. (2017)	26 [23]	22-119,577	Mix of quantitative and qualitative designs (In published literature: 7 quant', 2 qual'. In unpublished/grey literature: 14 quant'.)	Effective (Dance, Yoga, Active Science sessions)	

6.6.2.3 Results: Household Adversity

A total of 32 articles focused on types of household adversity and were grouped together based on this. Of these 32, the primary ACE for each was as follows:

- parent or guardian mental health problems (n=18) (Barlow, Bennett, Midgley, Larkin, & Wei, 2015; Bee et al., 2014; Beresford et al., 2008; J. Chen, Chen, Leung, & Tsang, 2021; Cuijpers, Weitz, Karyotaki, Garber, & Andersson, 2015; Gunlicks & Weissman, 2008; Havinga et al., 2021; Leijten et al., 2019; Letourneau, Dennis, Cosic, & Linder, 2017; Loechner et al., 2018; Marie-Mitchell & Kostolansky, 2019; Newton, Taylor Buck, Weich, & Uttley, 2020; Oja, Edbom, Nager, Månsson, & Ekblad, 2020; Poobalan et al., 2007; Rayce, Rasmussen, Skovgaard Væver, & Pontoppidan, 2020; Reupert et al., 2013; Siegenthaler, Munder, & Egger, 2012; Thanhäuser, Lemmer, de Girolamo, & Christiansen, 2017);
- parent or guardian substance misuse (n=6) (Ahern, Mechling, Palumbo, & Woodard, 2020; Bröning et al., 2012; Calhoun, Conner, Miller, & Messina, 2015; Niccols et al., 2012; Phillips, Gleeson, & Waites-Garrett, 2009; Ruff, McComb, Coker, & Sprenkle, 2010);
- parental imprisonment or probation (n=2) (Nilsen, Johansen, Blaasvær, Hammerstrøm, & Berg, 2015; Troy, McPherson, Emslie, & Gilchrist, 2018);
- parental separation or divorce (n=2) (Poli, Molgora, Marzotto, Facchin, & Cyr, 2017; Templer, Matthewson, Haines, & Cox, 2017); and
- bereavement (n=4) (Bergman, Axberg, & Hanson, 2017; C. Y.-C. Chen & Panebianco, 2018; de López, Søndergaard Knudsen, & Hansen, 2020; Journot-Reverbel, Raynaud, Bui, & Revet, 2017).

More specific information about the ACEs, any secondary ACEs and other participant characteristics are also detailed in Appendix C.4: Table 64. As shown in Table 38, these studies ranged in quality from 1.5 to 13 (out of 14) on the AMSTAR 2 quality appraisal tool; the median rating was 6.5 for all studies of household adversity. However, when separated by specific household adversity type, the AMSTAR 2 median ratings were as follows: parental or guardian mental health problems: 8.75; parent or guardian substance misuse: 3; parental imprisonment or probation: 5.75; parental separation or divorce: 2.75; bereavement: 4. The 32 systematic reviews on household adversity were made up of primary papers with various study designs.

Based on 18 systematic reviews, interventions for young people whose parent or guardian had a mental health problem tended towards mixed results, with some showing effectiveness. Often, these interventions were aimed at the affected parent or guardian, for example, delivering therapy,

counselling, or other psychosocial interventions to them, as a means of indirectly supporting the affected child too. Other interventions did directly involve the child, either alone or in combination with their parents. For example, there were school support interventions, youth group interventions, psychoeducation on their parent's condition, and CBT for 'at-risk' children, among others, and some interventions targeted the parent-child relationship, for example, through parent training, video feedback, infant massage, and family therapy. Finally, perinatal mental health featured in several of the systematic reviews, with interventions to promote maternal wellbeing, parental sensitivity and mother-baby bonding.

Six systematic reviews reported on interventions for young people whose parent or guardian had a substance misuse problem, and the findings tended towards being effective. These interventions included support groups and school support for the young person, and family therapy or couples therapy.

Only two systematic reviews were found which focused on interventions to support the mental health of young people with parents in prison or on probation; these showed mixed/inconclusive results. The included interventions took place within the criminal justice system and consisted of parenting programmes, family support programmes, support groups for children, and prison nurseries.

Only two systematic reviews focused on young people who had experienced parental separation or divorce. Group interventions to support children seemed effective. In more extreme cases of parental alienation, court intervention was the intervention described, for example, changes to custody/access arrangements and visitation, court-mandated systemic family therapy, psychoeducation, and parenting skills/coping skills. The findings for this latter intervention were predominantly focused on the alienated parent's wellbeing, and findings for the affected child were inconclusive.

Finally, four systematic reviews focused on young people who had experienced the death of a parent or guardian, or in some cases, a sibling or other close relative. Included interventions were support programmes like camps, parental guidance, play therapy or expressive arts therapy, family therapy, CBT and group interventions like support groups or group counselling. Many of these interventions utilised a group support format, perhaps to allow bereaved children and/or their surviving parent to share their experiences of bereavement with others in a similar situation. The interventions in this section tended to be mixed or effective in terms of the child's mental health outcomes.

Table 38: Quality appraisal of studies (Household Adversity)

	Reference	Raters	Question																Score /14	Score /11
			1	2	3*	4	5	6	7	8	9	10	11**	12**	13	14*	15*	16		
Mental Health Problems	Barlow et al. (2015)	P	1	0.5	0	1	1	1	1	1	1	0	0	1	1	1	0	1	10.5	9.5
	Bee et al. (2014)	L	1	1	1	1	1	1	1	1	1	0	1	1	1	1	1	1	13	10
	Beresford et al. (2008)	L	1	0.5	0	1	1	1	0	1	1	0	X	X	1	X	X	1	8.5	8.5
	Chen et al. (2021)	P	0	0	0	1	1	1	1	1	0.5	0	X	X	0	1	X	1	7.5	6.5
	Cuijpers et al. (2015)	P	1	0	1	1	0	0	1	1	1	0	1	0	1	1	1	0	9	6
	Gunlicks & Weissman (2008)	L	1	0	0	0.5	0	0	0	0.5	0	0	X	X	0	X	X	1	3	3
	Havinga et al. (2021)	P	1	0	0	1	1	1	1	1	1	0	1	0	0	0	1	1	9	8
	Leijten et al. (2019)	P	1	0	0	0	0	0	1	1	0	1	0	0	0	1	0	1	6	5
	Letourneau et al. (2017)	P	1	0	0	0	1	1	0.5	1	1	0	1	0	1	1	0	1	8.5	7.5
	Loechner et al. (2018)	L	1	0	0	1	0	1	0	0.5	1	0	1	0	0	1	1	1	7.5	5.5
	Marie-Mitchell & Kostolansky (2019)	P	1	0	1	1	1	1	1	1	1	0	X	X	0	0	X	1	9	8
	Newton et al. (2020)	P	1	0	0	1	0	1	1	1	1	0	X	X	1	1	X	1	9	8
	Oja et al. (2020)	P	1	0	1	0.5	1	1	1	1	0.5	0	X	X	0	1	X	1	9	7
	Poobalan et al. (2007)	P	1	0	0	1	1	1	1	1	1	0	X	X	0	1	X	1	9	8
	Rayce et al. (2020)	P	1	0	1	1	1	1	0.5	1	1	0	1	0	0	1	0	1	9.5	7.5
	Reupert et al. (2012)	L	1	0	0	0.5	0	0	0	0.5	0	0	X	X	0	X	X	1	3	3
	Siegenthaler, Munder & Egger (2012)	L	1	0	0	1	0	0	0	0	1	0	1	0	0	1	1	0	5	3
	Thanhäuser et al. (2017)	L	1	0	1	1	0	1	0	0	1	0	1	0	0	1	1	1	8	5
Substance Misuse	Ahern et al. (2021)	P	0	0	0	0.5	0	0	1	1	0	0	X	X	0	0	X	1	3.5	3.5
	Broning et al. (2012)	L	1	0	0	0.5	1	0	0	1	1	0	X	X	1	X	X	1	6.5	6.5
	Calhoun et al. (2015)	L	1	0	0	0.5	0	0	0	0.5	0	0	X	X	0	X	X	0	2	2
	Niccols et al. (2012)	L	1	0	0	1	0	1	0	0	1	0	X	X	0	X	X	0	4	4
	Phillips, Gleeson & Waites-Garrett (2009)	L	1	0	0	0.5	0	0	0	0	0	0	X	X	0	X	X	0	1.5	1.5
	Ruff et al. (2010)	L	1	0	0	0.5	0	0	0	0	0	0	X	X	1	X	X	0	2.5	2.5

Prison	Nilsen et al. (2015)	P	1	0	0	1	0	1	0	1	0	0	X	X	1	0	X	0	5	5
	Troy et al. (2018)	L	1	0	1	0.5	1	1	0	0	1	0	X	X	0	X	X	1	6.5	5.5
Sep'	Poli et al. (2017)	L	1	0	0	0.5	0	1	0	0.5	0	0	X	X	0	X	X	0	3	3
	Templer et al. (2017)	L	1	0	0	0.5	0	1	0	0	0	0	X	X	0	X	X	0	2.5	2.5
Bereavement	Bergman, Axberg & Hanson (2017)	L	1	0	0	0.5	1	0	0	1	0.5	0	X	X	0	X	X	1	5	5
	Chen & Panebianco (2018)	L	1	0	0	0.5	1	0	0	0.5	0	0	X	X	0	X	X	0	3	3
	De López, Søndergaard Knudsen & Hansen (2020)	P	1	0	1	0	1	0	1	1	0	0	X	X	0	1	X	1	7	5
	Journot-Reverbel et al. (2017)	L	1	0	0	0.5	0	0	0	0.5	0	0	X	X	0	X	X	1	3	3

Mental Health Problems = parent or guardian mental health problems; **Substance Misuse** = parent or guardian substance misuse; **Prison** = parental imprisonment or probation; **Sep'** = parental separation or divorce

Table 39: Study characteristics and summary of findings (Household Adversity)

Reference	Number of primary studies [N of articles]	Sample range ^{II}	Study designs of primary studies	Summary finding for mental health outcomes (with intervention type/focus)	Effectiveness RAG rating
Parent or Guardian Mental Health Problems					
Barlow et al. (2015)	8 [19]	59-193 parent-child dyads	RCTs	Ineffective for mental health outcome, but was promising for attachment relationship (Parent-Infant Psychotherapy)	
Bee et al. (2014) – chapter 4	11 [NS]	7-129	Mixed: 3 RCTs, 4 NRCTs, 4 uncontrolled	Mixed (psychotherapy); Mixed (CBT); Mixed (psychoeducation); Ineffective (extended care/health home visiting)	
Bee et al. (2014) – chapter 5	41 [58]	8-903	Mixed: 26 RCTs, 4 NRCTs, 11 uncontrolled	Mixed (psychotherapy); Effective (CBT); Mixed (psychoeducation); Ineffective (psychosocial intervention); Mixed (group counselling)	
Beresford et al. (2008)	37 [40]	NS	Mixed: 12 RCTs, 22 NRCTs	Effective (CBT for children of depressed parents who are at risk); Ineffective (CBT for children of depressed parents who were themselves depressed or ‘at risk’ for depression)	
Chen et al. (2021)	33 [33]	5-186	Mixed: RCTs, controlled and not specified	Results not reported (Child-Oriented Family Nursing Intervention); Effective (family therapy);	

				Effective (psychological counselling)	
Cuijpers et al. (2015)	9 [9]	16-235	RCTs	Effective (psychotherapy with mothers who had depression)	
Gunlicks & Weissman (2008)	10 [12]	10-260	Mixed: 6 RCTs, 4 open trial/observation	Effective (range of interventions for parental depression including therapies and medication)	
Havinga et al. (2021)	8 [22]	30-316	RCTs	Effective (prevention programmes combining psychoeducational elements with skills training and/or CBT elements)	
Leijten et al. (2019)	10 [10]	NS (total = 1280 families)	Randomised trials	Effective (Incredible Years)	
Letourneau et al. (2017)	36 [39]	NS	Mixed: RCTs and quasi-experimental studies	Mixed tending towards effective (for women with postpartum depression: interpersonal therapy [IPT]; CBT; maternal-child interaction guidance; massage; psychotherapeutic group support)	
Loechner et al. (2018)	7 [14]	24-316	RCTs	Effective in short-term, ineffective in long-term (preventive interventions, involving psychoeducation or CBT, for offspring of depressed parents, including: Family Talk Intervention [FTI]; Coping with Depression [CWD]; Raising Healthy Children [RHC]; Parenting training [PT])	
Marie-Mitchell & Kostolansky (2019)	20 [22]	27 mothers - 1173 children	RCTs	Effective (multi-component, varied interventions. In particular, multicomponent medium- to high-intensity interventions that utilised professional home visitors to provide parenting education or mental health counselling demonstrated largest effects)	
Newton et al. (2020)	16 [16]	20-193 mothers	Mixed: interventional studies with control group (12 RCTs, 4 others with a control arm)	Mixed (perinatal mental health interventions, including: group therapy; infant massage; video feedback; CBT for mother; psychodynamic therapy and non-directive counselling; strengths-based intervention; mind-mindedness video feedback; parent-infant psychotherapy)	
Oja et al. (2020)	32 [32]	5-390 (total of 3639 children or families, of which 2558	Mixed: 21 quantitative, 11 qualitative	Effective (interventions to support children with an ill parent, e.g. family interventions or peer interventions)	

		[70.3%] met our criteria)			
Poobalan et al. (2007)	8 [9]	20-193 mothers	Mixed: RCTs and controlled clinical trials	Effective (various treatments for postnatal depression, including: toddler parent psychotherapy; counselling; CBT; interpersonal therapy [IPT] etc)	
Rayce et al. (2020)	7 [8]	42-190 mothers	Mixed: RCTs and quasi-RCTs	Mixed tending towards ineffective (parenting interventions with a mixture of modalities, including: CBT; psychodynamic therapy etc)	
Reupert et al. (2012)	NS [25]	10 children - 375 families	Mixed: 10 RCTs, 7 pretest-posttest groups, 2 interviews, 1 feedback only, 1 questionnaire	Effective (family intervention programmes focusing on minimising family dysfunction and maximising children's support networks); Inconclusive (peer support groups); Inconclusive (online interventions); Inconclusive (Bibliotherapy)	
Siegenthaler, Munder & Egger (2012)	13 [17]	30-316	RCTs	Mixed, depending on mental health outcome (split as such below): Internalising symptoms: Effective (youth group-based intervention; couple-based intervention with parental skills training and family group-based intervention); Ineffective (parent group-based intervention; mother-based intervention); Externalising symptoms: Effective (mother-based intervention; mother group-based intervention; couple-based intervention; parent group-based intervention; couple-based intervention with parental skills training); Ineffective (family based intervention; youth group-based intervention)	
Thanhäuser et al. (2017)	53 [96]	14-674	RCTs	Mixed (psychosocial interventions, including: school-based support group; structural ecosystems therapy;	

				parent-group therapy; behavioural couple therapy; child outreach programme; family depression programme; group-based CBT; relational psychotherapy mother group; preventative parent training; play therapy; parent skill training with behavioural couple therapy)	
<i>Parent or Guardian Substance Misuse</i>					
Ahern et al. (2021)	12 [12]	11-420	Mixed: RCTs, qualitative and mixed methods	Effective (School-Based Support Groups); Mixed (Teen Club); Effective (Friends in Need); Effective (CHOICES); Effective (Trampoline intervention)	
Broning et al. (2012)	13 [13]	11 children - 280 families	Mixed: 7 RCTs, 2 controlled or quasi-experimental studies, 3 descriptive studies, and 1 qualitative study	Mixed (interventions for children with substance misusing parents, including school-based interventions, community-based intervention, and family-based interventions. Called Stress Management and Alcohol Awareness Programme [SMAAP]; Friends in Need; Children Having Opportunities in Courage; Esteem and Success [CHOICES]; Teen Club; School-Based-Support-Groups [SBSG]; Focus on Families [FOF]; Strengthening Families Programme [SFP, Utah-Version]; Family Competence Programme [FCP]; Safe Haven Programme)	
Calhoun et al. (2015)	4 [4]	30-151	RCTs	Effective (Parent Skills with Behavioural Couples Therapy); Effective (Behavioural Couples Therapy); Effective (Parents Under Pressure intervention)	
Niccols et al. (2012)	13 [13]	NS	Mixed: 2 randomised trials, 3 quasi-experimental studies, 8 cohort studies	Effective (Integrated programmes for mothers with substance abuse issues)	

Phillips, Gleeson & Waites-Garrett (2009)	6 [6]	11-253	NS	Inconclusive (substance abuse treatment for parents)	
Ruff et al. (2010)	23 [23]	34-303 parents	Mixed: most clinical trials, others unclear; most had a control group	Effective (Behavioural Couples Therapy for treatment of substance abuse)	
Parental Imprisonment or Probation					
Nilsen et al. (2015)	22 [19]	NS	Mixed: 5 RCTs, 17 NRCTs	Inconclusive (parenting interventions); Inconclusive (prison nurseries); Inconclusive (support groups for children)	
Troy et al. (2018)	29 [29]	12-476	Mixed: 1 qualitative study, 18 quantitative studies with and without a control group, and 10 mixed methods studies. (Of the quantitative: 14 quasi-experimental, 9 pretest-posttest design, 3 RCTs, 2 retrospective studies, 1 cohort study)	Mixed (parenting and family support programmes in the criminal justice system)	
Parental Separation or Divorce					
Poli et al. (2017)	29 [29]	8-188	Mixed: 11 RCTs, 10 quasi-experimental, 6 repeated measure designs (pretest-posttest design), 1 single case study, 1 had an exclusive focus on the intervention process	Effective (group interventions to support children whose parents have separated)	
Templer et al. (2017)	10 [10]	21-99	Mixed: mainly case-series, 1 quasi-experimental study	Inconclusive (parental alienation interventions including court intervention e.g. changes to custody/access arrangements and visitation; court-mandated systemic family therapy; psychoeducation; parenting skills/coping skills).	
Bereavement					
Bergman, Axberg & Hanson (2017)	17 [17]	38-244	Mixed: 1 quasi-experimental, 1 had pretest-posttest design, the remainder were RCTs	Mixed (support programmes, including: group interventions for children; family interventions; guidance for parents; camp activities for children)	
Chen & Panebianco (2018)	17 [17]	1-113	Mixed: 2 RCT, the remainder were pretest-posttest or post-intervention	Effective (play therapy; expressive arts therapy [depending on mental health outcome]; other interventions e.g. camp);	

				Inconclusive (CBT; family therapy); Ineffective (combined play therapy; expressive arts therapy; group counselling techniques)	
De Lopez, Søndergaard Knudsen & Hansen (2020)	8 [8]	22-353	Mixed: 6 random and 2 semi-random assignment control group studies	Effective (grief treatments, including: family sessions; independent group sessions for child and surviving parent)	
Journot-Reverbel et al. (2017)	2 [2]	8-102	Mixed: 1 RCT, 1 pretest-posttest group therapy	Effective (psychosocial support groups for suicide-bereaved children)	

6.6.2.4 Results: Involvement with Child Protective Services (CPS) or Living in Care

A total of 28 articles focused on types of involvement with child protective services (CPS) or living in care, and were grouped together based on this. Involvement with CPS included being a looked-after child (LAC), being in residential, out-of-home or institutional care, foster care, kinship care and in some cases, adoption. Due to the highly overlapping nature of these labels (and the corresponding papers and their populations), the results in this section are grouped together rather than split into different forms of CPS involvement. As illustrated in Appendix C.4: Table 65, though involvement with CPS was classed as the primary ACE for presentation purposes, in most instances this was preceded by exposure to other ACEs, in the form of some sort of maltreatment or neglect.

The articles in this section (n=28) were from the following authors: (Bailey et al., 2018; Bergström et al., 2020; Everson-Hock et al., 2011, 2012; Galvin et al., 2022; Grube & Liming, 2018; Hambrick, Oppenheim-Weller, N'zi, & Taussig, 2016; Heerde, Hemphill, & Scholes-Balog, 2018; Hermenau, Goessmann, Rygaard, Landolt, & Hecker, 2017; James, Alemi, & Zepeda, 2013; Kemmis-Riggs, Dickes, & McAloon, 2018; Kerr & Cossar, 2014; Kinsey & Schlösser, 2013; Liabo, Gray, & Mulcahy, 2013; Maclean, Sims, O'Donnell, & Gilbert, 2016; Marcellus, MacKinnon, Gordon, & Shaw, 2021; Roberts, Maxwell, Rees, Holland, & Forbes, 2016; SBU Assessments, 2017; Schoemaker et al., 2020; Solomon, Niec, & Schoonover, 2017; Turner, Macdonald, & Dennis, 2007; Uretsky & Hoffman, 2017; Van Andel, Grietens, Strijker, Van der Gaag, & Knorth, 2014; Wilson & Barnett, 2020; Winokur, Holtan, & Batchelder, 2014, 2018; Xu & Bright, 2018; Ziviani, Feeney, Cuskelly, Meredith, & Hunt, 2012).

As shown in Table 40, these studies ranged in quality from 2.5 to 12 (out of 14) on the AMSTAR 2 quality appraisal tool; the median rating was 6.5. The 28 systematic reviews were made up of primary papers which utilised a variety of study designs, including RCTs, pretest-posttest, experimental, quasi-experimental, longitudinal, and prospective designs.

As can be seen in Table 41, there were a wide variety of interventions for young people involved with CPS. Training for foster and adoptive parents featured especially prevalently across different studies. In particular, Attachment and Biobehavioural Catch-Up (ABC), Incredible Years (IY), and Keeping Foster and Kin Parents Supported and Trained (KEEP) featured in multiple systematic reviews. Both attachment-based (or parent-child dyad) and trauma-informed interventions were also common, for example, the ABC intervention, the Sanctuary model and trauma-focused CBT interventions. This could be suggestive of the underlying theory of change or mechanism for effectiveness posited by these interventions i.e. that promoting attachment relationships and enhancing (foster or adoptive)

parent-child interactions, and/or considering the trauma histories of these young people, may be a helpful way to support them. Other interventions sought to support outcomes such as educational attainment and transitions (such as transitioning out of care), but also reported on mental health and wellbeing outcomes, hence being included in this review.

Though the present umbrella review excluded systematic reviews which clearly focused on treatment (as opposed to prevention or early intervention), the distinction for this group of young people was more complex, and several of the interventions did draw on a therapeutic modality (i.e. were underpinned by or based on therapy/treatment principles). It is possible this was due to a recognition that young people involved with CPS are at significant risk for poorer outcomes, such as poor mental health outcomes, and as such, interventions were more intensive or therapeutic, as is proportionate to their increased needs. We included reviews where these interventions seemed to be used in a more proactive way (rather than reactive to problems) as far as could be deduced from the systematic reviews. For example, there were groups for families and young people which were based on a therapeutic modality, but seemingly being used in a preventative or early intervention way. These included some interventions which were classed as ‘psychosocial’ in nature or based on therapeutic modalities such as cognitive-behavioural therapies (CBT), family therapy, dialectical behavioural therapy (DBT), and solution focused brief therapy (SFBT).

As in the abuse and neglect category reported previously, the child was not always the direct or sole target of intervention in this case either; many interventions focused on helping the young people with CPS involvement by supporting their foster parent or caregiver, or by working with the (foster or adoptive) parent and child as a dyad.

On the whole, early interventions seemed to show promise for mitigating poor mental health outcomes in young people who were involved with CPS, with results tending towards mixed or effective. Important exceptions were found that suggested potential ineffectiveness, and in some cases harmful outcomes, from non-kinship care, instead favouring kinship care. However, this is heavily caveated with study design limitations, such as the risk of selection bias in which young people were offered kinship versus non-kinship care, and it was also unclear whether kinship care would be favourable in the longer term. Finally, the evidence on transition support services was more mixed or inconclusive in terms of their effectiveness for mental health outcomes. For more details of study designs, intervention types and a summary of findings, see Table 41.

Table 40: Quality appraisal of studies (Involvement with Child Protective Services (CPS) or Living in Care)

	Reference	Raters	Question																Score /14	Score /11
			1	2	3*	4	5	6	7	8	9	10	11**	12**	13	14*	15*	16		
Involvement with Child Protective Services (CPS) or Living in Care	Bailey et al. (2018)	P	0	0	0	1	1	0	1	1	0.5	1	X	X	1	1	X	0	7.5	6.5
	Bergström et al. (2020)	P	1	0	0	1	1	1	1	1	1	0	X	X	1	1	X	1	10	9
	Everson-Hock et al. (2011)	L	1	0	0	1	1	1	0	0.5	1	0	X	X	1	X	X	0	6.5	6.5
	Everson-Hock et al. (2012)	L	1	0	0	0.5	1	1	0	0.5	1	0	X	X	1	X	X	0	6	6
	Galvin et al. (2021)	P	1	0.5	0	1	1	0	1	1	1	1	X	X	1	1	X	1	10.5	9.5
	Grube & Liming (2018)	P	1	0	1	1	1	1	1	1	1	0	X	X	1	1	X	0	10	8
	Hambrick et al. (2016)	L	1	0.5	0	0.5	1	1	0	0	1	0	X	X	0	X	X	0	5	5
	Heerde et al. (2018)	P	0	0	1	1	0	1	0.5	1	0	0	0	0	0	1	1	1	7.5	4.5
	Hermenau et al. (2017)	P	1	0	1	1	0	0	1	1	0	0	X	X	1	0	X	1	7	6
	James, Alemi & Zepeda (2013)	P	1	0	1	0.5	1	0	1	1	1	0	0	X	1	1	X	1	9.5	7.5
	Kemmis-Riggs, Dickes & McAloon (2018)	L	1	1	0	0.5	1	1	0	0.5	1	0	X	X	0	X	X	0	6	6
	Kerr & Cossar (2014)	L	1	0	0	1	0	1	0	0.5	1	0	X	X	0	X	X	0	4.5	4.5
	Kinsey & Schlösser (2013)	L	1	0	0	0.5	0	1	1	0.5	1	0	X	X	0	X	X	1	6	6
	Liabo, Gray & Mulcahy (2013)	L	1	0	0	1	1	0	0	0.5	0	0	X	X	0	X	X	0	3.5	3.5
	Maclean et al. (2016)	L	1	0	0	0.5	1	1	0	1	1	0	X	X	1	X	X	0	6.5	6.5
	Marcellus et al. (2021)	P	0	0	0	1	1	1	1	1	0	0	X	X	0	0	X	1	6	6
	Roberts et al. (2016)	L	1	0	0	1	0	0	0	0.5	1	0	X	X	0	X	X	0	3.5	3.5
	SBU Assessments (2017)	P	0	0	1	0.5	0	0	0	0.5	1	0	X	X	1	1	X	0	5	3
	Schoemaker et al. (2020)	P	1	0	0	0.5	1	1	1	1	0	0	1	0	0	1	1	1	8.5	6.5
	Solomon, Niec & Schoonover (2017)	L	1	0	0	0.5	0	0	0	0.5	0	0	1	0	0	1	0	1	4	3
	Turner, Macdonald & Dennis (2007)	L	1	1	0	1	1	0	1	1	1	0	1	0	0	1	0	1	9	8
	Uretsky & Hoffman (2017)	L	1	0	0	0.5	0	1	1	0	0	0	1	0	1	0	0	0	4.5	4.5
	Van Andel et al. (2014)	L	1	0	0	0.5	0	0	0	0	0	0	1	0	0	1	X	0	2.5	1.5
	Wilson & Barnett (2020)	P	0	0	0	0.5	1	0	1	1	0.5	0	X	X	1	1	X	1	7	6

Winokur, Holtan & Batchelder (2014)	L	1	1	0	1	1	1	1	1	1	0	1	1	1	1	1	1	12	10
Winokur, Holtan & Batchelder (2018)	P	1	0	1	0	1	1	1	1	1	0	0	1	1	1	1	1	11	8
Xu & Bright (2018)	P	1	0	0	1	1	0	1	1	0.5	0	X	X	1	1	X	1	8.5	7.5
Ziviani et al. (2012)	L	1	0.5	0	0.5	1	0	0	1	1	0	X	X	0	X	X	1	6	6

Table 41: Study characteristics and summary of findings (Involvement with Child Protective Services CPS) or Living in Care)

Reference	Number of primary studies [N of articles]	Sample range	Study designs of primary studies	Summary finding for mental health outcomes (with intervention type/focus)	Effectiveness RAG rating
<i>Involvement with Child Protective Services (CPS) or Living in Care</i>					
Bailey et al. (2018)	7 [7]	0-481 (in the case of 0 young people, staff members were sampled instead)	Mixed: naturalistic study designs (including programme evaluation and semi-structured naturalistic approach), multiple baseline interrupted time series, qualitative (including observation of groups, content analysis, interviews, focus groups), comparison group design	Effective (ARC); Inconclusive (CARE); Effective (Sanctuary model)	
Bergström et al. (2020)	23 [28]	46-834	Mixed: 20 RCTs, 3 non-randomised longitudinal	Inconclusive – no studies (foster parent selection); Inconclusive – no studies (basic preservice foster parent training); Mixed (interventions targeting foster children or foster parents, specifically: Attachment and Biobehavioural Catch-up [ABC]; Incredible Years Parenting Programme; Take Charge for young people)	
Everson-Hock et al. (2011)	7 [7]	67-810	Mixed: 5 retrospective cohort, 2 prospective cohort	Ineffective (transition support services [TSSs])	
Everson-Hock et al. (2012)	NS [6]	53 children-carer dyads - 700 carers	Mixed: 5 RCT, 1 prospective cohort	Mixed (training and support for approved foster carers, professionals and volunteers; focus of training and support was on the physical and emotional health and wellbeing of looked-after children)	
Galvin et al. (2021)	4 [4]	1-1036	Mixed: 2 RCTs, 1 case study, 1 case-control	Effective (interventions and practice models to improve the health and psychosocial outcomes of children in residential out-of-home care, specifically: Cognitive Behaviour Treatment [CBT]; Healthy Eating Active Living [HEAL]; Power Through Choices [PTC]; Alternate Care Clinic [ACC])	
Grube & Liming (2018)	3 [10]	46-164	RCTs (majority used pretest-posttest design, 3 used longitudinal design)	Effective (Attachment and Biobehavioural Catch-Up [ABC])	

Hambrick et al. (2016)	39 [39]	NS	Mixed: RCTs plus other evaluations where needed (NB: authors note they included other less rigorous designs than RCTs if the intervention was supported by an RCT in at least one population)	Effective (mental health interventions for children in foster care. Specifically: Attachment and Biobehavioural Catch-Up [ABC]; Child Parent Psychotherapy [CPP]; Fostering Healthy Futures [FHF]; Incredible Years [IY]; Keeping Foster Parents Trained and Supported [KEEP]; Kids in Transition to School [KITS]; Parent-Child Interaction Therapy [PCIT]; Short Enhanced Cognitive-Behavioural Parent Training [CEBPT]; Trauma-Focused Cognitive Behavioural Therapy [TF-CBT]; Treatment Foster Care Oregon for Preschoolers [TFCO-P; formerly Multidimensional Treatment Foster Care for Preschoolers]; Effective (interventions with preventative benefits were: FHF; IY; TFCO-P)	
Heerde et al. (2018)	19 [9]	23-1082	Qualitative and quantitative analysis of case records	Inconclusive (interventions to support transition out of care)	
Hermenau et al. (2017)	24 [22]	13-132	Mixed: RCTs, matched control	Effective (structural interventions and caregiver training in institutional care settings)	
James, Alemi & Zepeda (2013)	13 [13]	14-522	Mixed: 6 RCTs, remainder used pretest-posttest design	Effective (psychosocial interventions, broadly defined as client-level interventions targeting mental health, substance abuse and/or social skills problems and differentiated from system-wide or milieu-based interventions. Specifically: Adolescent Community Reinforcement Approach [CRA]; Aggression Replacement Training; Dialectical Behavioural Therapy [DBT]; Ecologically-Based Family Therapy; Eye Movement Desensitisation and Reprocessing Therapy [EMDR]; Functional Family Therapy; Multimodal Substance Abuse Prevention; Residential Student Assistance Programme; Solution-Focused Brief Therapy [SFBT]; Trauma Intervention Programme for Adjudicated and At-Risk Youth)	
Kemmis-Riggs, Dickes & McAloon (2018)	17 [28]	22-700	RCTs: 12 single RCTs, the other 2 double/triple. Only 2 used active controls	Mixed (psychosocial interventions in foster and kinship care. Specifically: promoting first relationships [PFR]; Attachment and Biobehavioural Catch-Up [ABC]; foster carer-foster child intervention [FFI]; Incredible Years basic parenting programme + co-parent adaptation [IY+CP];	

				Keeping Foster Parents Trained and Supported [KEEP]; Short Enhanced Cognitive-Behavioural Parent Training [CEBPT]; Cognitive-Behavioural Parent Training [CBT-PT]; Kids in Transition to School [KITS]; Middle School Success [MSS]; Promoting Sibling Bonds [PSB]); Effective (Parent-Child Interaction Therapy [PCIT]); Ineffective (Incredible Years basic parenting programme [IY]; Parent Management Training Oregon [PMTO])	
Kerr & Cossar (2014)	10 [13]	7-147	Mixed: pretest-posttest intervention studies, longitudinal follow-up, controlled studies, and RCTs	Mixed tending towards effective (attachment-theory based interventions with foster and adoptive parents. Specifically: Attachment and Biobehavioural Catch-Up [ABC]; parental sensitivity intervention; fostering attachments group; managing behaviour with attachment in mind group; child-parent relationship therapy group, including play therapy components; Dyadic Developmental Psychotherapy)	
Kinsey & Schlösser (2013)	20 [30]	24 children - 700 foster families	Mixed: post intervention, pretest-posttest intervention, RCTs, between groups comparison	Ineffective (pure carer training interventions); Mixed (relational interventions); Effective (wraparound services)	
Liabo, Gray & Mulcahy (2013)	11 [11]	10-765	Mixed: 6 before-after evaluations without a comparison group, 4 policy evaluations of implementation processes and outcomes, and 1 before-after study with a non-equivalent comparison group	Mixed (interventions to support looked-after children in school. Specifically: Taking Care of Education; Virtual School Head; Community Project; Residential School; pilot of spending targeted money; intervention by an education liaison)	
Maclean et al. (2016)	11 [31]	136-29,751	Mixed: prospective and retrospective cohort	Mixed tending towards ineffective or harmful in some cases (out-of-home care vs in-home care; results favour the latter, though selection bias, lack of randomisation and lack of well-matched cases all limit conclusions)	
Marcellus et al. (2021)	NS [81]	1-551,232	Mixed: RCTs, retrospective, longitudinal or qualitative	Effective (Attachment and Biobehavioural Catch-Up [ABC]; Foster Family intervention; New Orleans Intervention Model; Promoting First Relationships intervention)	

Roberts et al. (2016)	12 [12]	46-700	Mixed: 4 RCTs, 1 pretest-posttest design	Effective (Fostering Changes); Effective (Fostering Healthy Futures Programme); Effective (Incredible Years for foster carers); Effective (KEEP); Effective (Paired reading literacy scheme)	
SBU Assessments (2017)	23 [NS]	46-834	Mixed: 20 RCTs, 3 CTs	Effective (Attachment and Biobehavioural Catch-Up [ABC]); Effective (Incredible Years [IY]); Effective (Take Charge intervention); Inconclusive (remaining 15 unspecified interventions for foster children)	
Schoemaker et al. (2020)	53 [NS]	14-881	Mixed: 40 RCTs, 12 quasi-experimental design, 1 unclear	Mixed (parenting interventions for foster and adoptive parents, including: KEEP; ABC; IY; CPRT; MTFC-P; video feedback and book; and family psychotherapy)	
Solomon, Niec & Schoonover (2017)	15 [16]	18-700	Mixed: 8 RCTs, others used unspecified design without randomisation	Mixed (foster parent training [FPT])	
Turner, Macdonald & Dennis (2007)	6 [6]	27-164	Mixed: 2 quasi-RCTs, 4 RCTs	Inconclusive (psychosocial educational group with foster carers); Inconclusive (CBT programme for foster carers); Inconclusive (mental health training for foster carers); Inconclusive (parenting programme with foster carers); Effective (training for foster carers in challenging behaviours);	

				Inconclusive (enhanced services and stipends for foster carers)	
Uretsky & Hoffman (2017)	11 [11]	13-906	Mixed: 5 RCTs, 4 quasi-experimental, 2 single pretest-posttest designs	Effective (group-based foster parent training programmes. Specifically: Incredible Years [IY]; Keeping Foster and Kin Parents Supported and Trained [KEEP]; Middle School Success programme; Cognitive Behavioural Parent training)	
Van Andel et al. (2014)	19 [15]	11-426	Mixed: mostly pretest-posttest design, some RCTs	Effective (family-based interventions; typically attachment theory-based and focus on increasing foster parents' sensitivity and responsiveness towards the foster child's needs)	
Wilson & Barnett (2020)	12 [12]	20-76	Mixed: 8 RCTs, 3 single group pretest-posttest trials, 1 qualitative	Mixed or effective, depending on mental health outcome (rhythmic exercise); Ineffective (yoga); Effective (water activities); Ineffective (martial arts or football); Ineffective (individual health programme and 'sports challenge'); Effective (initiative or general recreation activities)	
Winokur, Holtan & Batchelder (2014)	102 [105]	NS (total = 666,615)	Quasi-experimental (cross-sectional and longitudinal)	Effective (kinship foster care > non-kinship foster care)	
Winokur, Holtan & Batchelder (2018)	102 [105]	NS	Quasi-experimental (cross-sectional and longitudinal)	Effective (kinship foster care)	
Xu & Bright (2018)	8 [8]	111-4,019	Mixed: 3 cross-sectional, 5 prospective longitudinal	Mixed (kinship foster care vs non-kinship foster care; typically favouring the former but unclear if effect is maintained over time as longitudinal studies of high quality did not support this)	
Ziviani et al. (2012)	4 [4]	103-173	Mixed: 2 RCTs, 2NRCTs	Mixed (support services for children in out-of-home care who also have a disability and challenging behaviours. Specifically: Fostering Individualised Assistance Programme [FIAP]; Parent-child interaction therapy [PCIT]; small group training on challenging behaviour management)	

6.6.3 Results for secondary research questions

The Results section above presents systematic results for every included paper. In contrast, the following Results sections present less systematic highlights from papers, selected based on offering the most useful information to help answer the secondary research questions of this umbrella review. The following sections cover three aspects:

- 1) Intervention characteristics:
 - a. Cohort identification
 - b. Targeting or modifications for different cohorts
- 2) Intervention outcomes:
 - a. Proposed mediators and moderators
 - b. Risks, unintended consequences or harms
 - c. Cost-effectiveness
- 3) Intervention implementation:
 - a. Barriers and enablers to successful implementation.

6.6.4 Intervention characteristics: Cohort identification

Due to the abstracted/overview nature of systematic reviews (compared to primary studies), the method of identifying eligible cohorts of young people to be offered prevention or early intervention support was rarely reported. However, a few papers did give examples of how cohorts were identified. These examples are outlined in Appendix C.4: Table 66, and were grouped as follows: Identified directly via young person; Identified indirectly via parent or caregiver; Identified via multiple sources. These examples illustrate that young people could be identified by services directly because of their exposure to an ACE; for example, being in foster care, being homeless, having a parent with mental health problems who is known to services, or co-location of ACE reporting and intervention services (via the Children's Advocacy Centre [CAC] model). Other identification methods included screening tools (for young people and parents), monitoring key periods of transition, recruitment via schools, triangulation of reporting, and one instance of a data-analytic approach (though details on this were lacking).

6.6.5 Intervention characteristics: Targeting or modifications for different cohorts

Few of the included systematic reviews contained information about the extent to which interventions were targeted or modified to different cohorts. This was likely because the systematic reviews, by their very nature, provided a synthesis of the interventions, so lack the detail of the primary studies. With this caveat in mind, a few systematic reviews did include examples of intervention modifications.

Modifications relating to the *young people* themselves consisted of modifications for:

- Sex;
- Age or developmental stage;
- Cultural or ethnic background;
- The specific ACE-exposure (such as using trauma-informed approaches and recognising trauma histories of young people in residential out-of-home care to prevent retraumatisation).

Modifications relating to *parents and caregivers* consisted of:

- Increasing the involvement of fathers in interventions;
- Joint training for foster parents alongside biological parents in a foster care intervention (in order to promote collaborative parenting relationships);
- Inclusion of additional intervention components for parents who abuse their children (e.g. anger and stress management);
- Tailoring systemic family therapy to parental alienation where this issue is present, plus court mandates and sanctions for the alienating parent.

Modifications relating to the *interventions themselves or the personnel delivering them* consisted of:

- Staffing and training (e.g. involving specific disciplines or providing enhanced training);
- Flexibility and timing (e.g. condensing, elongating or only using components of interventions).

Other systematic reviews noted the lack of evidence regarding intervention modifications and made recommendations for such tailoring. Examples included modifications to improve the cultural sensitivity of interventions, or to meet the needs of especially at-risk groups. Further detail of modifications, with examples and corresponding references, are included in Appendix C.4: Table 67.

6.6.6 Intervention outcomes: Proposed mediators and moderators (for effectiveness, ineffectiveness and neutrality)

In the protocol for this umbrella review, we stated our intention to explore the mechanisms for effective, ineffective and neutral intervention impact. This was included in order to understand what processes mediated whether or not an intervention was successful so that this learning could be taken forward into future interventions. These mediators could either be tested or just posited, but untested by the paper authors. However, during the review process, it was not possible to isolate mediators (i.e. processes or events responsible for change) from moderators (i.e. factors influencing the direction

or magnitude of effects) in many cases and as such, both are reported in Table 42 overleaf. The table provides examples of mediators and moderators, with relevant paper(s) cited after each example; examples are grouped by type of factor (e.g. child-specific factors; parent- or caregiver-specific factors; intervention-specific factors etc).

Table 42: Examples of proposed mediators and moderators, grouped by factor type

Temporal factors
The passage of time may be important because interventions effects may happen gradually over time. For example, in the case of interventions whose outcomes are dependent on the development and interaction of parent and child behaviours over time (Schoemaker et al., 2020).
Organisational or structural factors
- Residential stability/instability may impact on intervention effectiveness (Bassuk et al., 2014; Hambrick et al., 2016). - High staff caseloads due to resource constraints led to a relatively minimal case management approach (Morton et al., 2020).
Intervention factors
- Intervention fidelity may enhance intervention outcomes. Intervention manuals may promote fidelity (Bailey et al., 2018; Gutterswijk et al., 2020). - Treatment intensity can have an impact – longer duration or inclusion of maintenance or ‘booster’ sessions may sustain and strengthen initial treatment gains (Coren et al., 2016). - Mismatches between interventions offered and children’s needs will affect outcomes. For example, offering exercises to reduce anxiety when no anxiety symptoms are present (Havinga et al., 2021). Similarly, in the case of an intervention whose best results were on reducing externalising behaviours, the effectiveness may have been reduced for girls because they are less likely to exhibit externalising problems in the first place (Ziviani et al., 2012). - Services provided by shelters were possibly not effectively targeting the underlying causes of the presenting symptoms, or were not comprehensively addressing the range of needs of families, thus hindering impact (Slesnick et al., 2009). - Lack of a coherent theory of change about how outcomes will be achieved may be problematic, with programmes instead relying more on a set of principles that are assumed to contribute holistically to intended outcomes (Herbert & Bromfield, 2016). Related to this idea of having a theory of change, many interventions did seem to be underpinned by a proposed mechanism for change, using attachment theory or taking trauma-informed approaches (see for example, Bailey et al., 2018; Grube & Liming, 2018; Hambrick et al., 2016; Indrayani et al., 2020; James et al., 2013; Kerr & Cossar, 2014; Lindstrom Johnson et al., 2018; Marcellus et al., 2021; Roberts et al., 2016; SBU Assessments, 2017; Schoemaker et al., 2020; Van Andel et al., 2014). Similarly, Schoemaker and colleagues found that parenting interventions can indirectly improve children’s attachment security and stress regulation by changing their internal working models, but this may be a time-consuming process that seems to start by increasing parents’ sensitive behaviour (Schoemaker et al., 2020). - Parenting interventions often utilise a group format and positive impact is achieved through the dual process of emotional experience and reflection in an interpersonal context. Group sessions: provide a support network; reduce isolation and stigma; provide an environment to practise interpersonal and communication skills, shape coping strategies, and learn from each other. All of these factors may be important for mothers with depression as they may feel alone with their problems (Rayce et al., 2020).

-
- Group interventions may be ineffective when a more individualised approach is required. For example, in instances where it is important to attend to the carers' own attachment styles and adapt treatment to meet the carers' needs, and ultimately the needs of the specific and unique interaction between a particular carer and particular child (Kinsey & Schlösser, 2013).
 - One systematic review noted that normative interventions, away from the home environment, may be helpful for care-experienced young people. It suggested that physical activity is one of the most normative and therefore readily available forms of social activity that young people can access. Moreover, as it is usually done outside the home, it can provide stability that the most vulnerable children in care tend not to receive from their placements. The authors posited this explained much of why physical activity interventions were effective in improving the health of children in care. In addition, they suggested the effectiveness of yoga for the health of children in Indian orphanages may have had more to do with its cultural and spiritual significance in that particular society (Wilson & Barnett, 2020).
-

Intervention deliverer factors

- Involvement of nurse practitioners and other healthcare providers moderated the success of the intervention, with reductions in involvement leading to reductions in effectiveness (Ahern et al., 2020).
 - The level of experience and training of the intervention delivery staff was an important factor (Poobalan et al., 2007).
-

Parent- or caregiver-specific factors

- Carers may experience vicarious trauma from caring for children in out-of-home care, making it harder for them to build meaningful relationships with the children (Bailey et al., 2018).
 - Caregiver engagement in the intervention may act as a moderator for success, though the direction of moderation was not always clear (Hambrick et al., 2016; Liabo et al., 2013).
-

Child-specific factors

- Treatment intensity should match the child's needs or level of difficulties (Kerr & Cossar, 2014). Many foster children have multiple and/or complex difficulties. Short-term training groups for carers might have little impact if they cannot adequately cover the variety and complexity of difficulties foster children experience (Kinsey & Schlösser, 2013).
 - The number of difficulties experienced by a young person may moderate the effectiveness of interventions. For example, when children experience multiple stressors such as loss of social support, issues with living conditions, among other stressors, this is more complex than when there is a single stressor (Nocon, Eberle-Sejari, Unterhitzberger, & Rosner, 2017; Rayce et al., 2020).
-

6.6.7 Intervention outcomes: Risks, unintended consequences or harms

Alongside intervention effectiveness, it was also essential to consider any risks, unintended consequences and harms associated with intervention participation. This was especially important for the present thesis as these findings have implications for taking a more data-driven screening approach to offering mental health support.

The most striking risk or unintended consequence highlighted in this umbrella review was when the intervention group did not significantly improve, or in fact did worse than the control group, which was documented in several primary studies included in the systematic reviews (for example, see Newton et al., 2020; Nocon, Eberle-Sejari, Unterhitzenberger, & Rosner, 2017; Solomon et al., 2017; Templer et al., 2017). Moreover, iatrogenic effects were identified by some systematic reviews, for young people and/or their caregivers. For example, Gutteriswijk and colleagues (2020) noted that residential youth care may cause harm when young people are exposed to institutional repression, negative peer influences, restricted autonomy and reduced need for self-determination. Similarly, Broning and colleagues (2012) found that in one of the high quality included studies within their systematic review, positive alcohol expectations increased among young people, despite the intended effect being the opposite. Likewise, in their systematic review of parenting and family support programmes delivered in the criminal justice system, Troy and colleagues (2018) cited a study that found men's attitudes to parenting became more negative and their mental health and wellbeing worsened following participation in the parenting programme. They posited that this could be explained by participating fathers engaging in more realistic appraisals of their parenting, resulting in feelings of guilt and remorse. They added that when 'good parenting' is modelled in parenting programmes, social comparison theory would suggest that parents who believe they fall short of this may experience negative internalising processes.

Related to iatrogenic effects, retraumatisation was highlighted as a risk of interventions. Bailey and colleagues (2018) noted that a failure to understand or address issues which arise from young people's traumatic histories prior to being in out-of-home care risks unintentionally aggravating symptoms and further traumatising these young people.

In addition, when interventions do not have the expected or hoped for impact, either for the young person or their parents, there is a risk that this reduces the likelihood that they seek mental health support if needed in future (Leijten et al., 2019). In their evaluation of the Incredible Years parenting programme, Leijten and colleagues further reflected that a lack of desired impact could potentially

increase parents' dysfunctional attributions that they do not have the ability to influence their child's behaviour or that their child is unwilling to change.

Finally, personal preference and the acceptability of the intervention was an important factor too. When working with children of parents with schizophrenia, Chen and colleagues (2021) found that not all children wanted to become more knowledgeable about mental illnesses; this was because they believed that such knowledge would make them feel worse, rather than better, about their situation. Similarly, for children of parents with a mental health problem more broadly, the identified potential risks of peer-support programmes included exposure to unsettling information about mental illness and limiting peer-support networks only to those in the programme (Reupert et al., 2013).

6.6.8 Intervention outcomes: Cost-effectiveness

Throughout the 82 included studies, there was a paucity of information on cost-effectiveness of prevention or early interventions for mitigating the impact of ACEs. In fact, several of the systematic reviews commented on the lack of cost-effectiveness data in primary studies and noted that this information should be included in future (Barlow et al., 2015; Bee et al., 2014; Bergström et al., 2020; Howarth et al., 2016; Montgomery et al., 2009; Morton et al., 2020; Niccols et al., 2012; SBU Assessments, 2017). Moreover, one study noted a responsibility to explore the cost-effectiveness of interventions which may be publicly funded, saying:

“The lack of rigorous evaluations of our public investments in shelters and housing to address homelessness means we are missing opportunities to spend our resources effectively and help our young people gain stable housing.” (Morton et al., 2020)

Howarth and colleagues (2016) wrote the only systematic review to include quantitative cost-effectiveness data relating to young people. For important context and completeness, I would strongly recommend referring to the original paper. However, an excerpt from their executive summary is included here. For each intervention arm, they analysed the number of sessions and estimated time for health and social care professionals, summing these in order to estimate the mean cost in staff time. They noted that insufficient information existed to include other resource costs, including the venue cost, or one-off staff training costs. In summary, Howarth and colleagues stated:

“None of the trials that we reviewed in this evidence synthesis conducted an economic analysis. Our analysis was based on the NMA, and, by virtue of this, the same strong assumptions. It was designed to inform research recommendations, not the implementation of one intervention over another.”

In terms of children's mental health outcomes, a psychoeducational intervention delivered to the child is likely to be most cost-effective [incremental cost-effectiveness ratio (ICER) > £858/SMD], although at a very high willingness-to-pay threshold (ICER > £22,575/SMD), cognitive-behavioural therapy may be equally cost-effective.

For children's behavioural outcomes, a psychoeducational intervention provided to parents and children in parallel is likely to be the most cost-effective at a lower willingness-to-pay threshold (ICER > £3782/SMD), with parenting skills plus advocacy becoming relatively more cost-effective at a higher willingness-to-pay threshold (ICER > £8017/SMD)." (Howarth et al., 2016)

NMA = network meta-analysis; **ICER** = incremental cost-effectiveness ratio; **SMD** = standardised mean difference

In addition, Bee and colleagues (2014) attempted to carry out cost-effectiveness searches as one of their explicit aims. However, they found no economic evaluations, or cost or resource-use studies for children of parents with serious mental illness (SMI). They identified one economic evaluation from a non-randomised evaluation of parental depression. Yet, they noted limitations of a high risk of bias and narrow assessment of costs and effects. Furthermore, they noted:

"the study focused on the costs and benefits from the perspective of the mother, so cannot be used to directly support resource allocation decisions to improve the QoL [quality of life] of children."

See Chapter 4 and 5 of their review for a comprehensive overview (Bee et al., 2014).

Though quantitative analysis was generally lacking, a small number of authors made qualitative speculations and hypotheses about the plausible cost-effectiveness of interventions, noting some of the potential cost savings. These are detailed in Table 43.

Table 43: Proposed potential cost-effectiveness

Reference	ACE	Comment
Gutterswijk et al. (2020)	Maltreatment (mixed)	“residential youth care is a very intensive and expensive type of youth care, restricting youths’ autonomy (James, 2017; Knorth et al., 2007), and their need for self-determination (Van der Helm et al., 2018). In general, a trajectory in TFCO-A is less expensive than a placement in secure residential youth care. TFCO-A, however, is slightly more expensive than a placement in residential youth care if length of stay is comparable (Åström et al., 2019). ...The results of this meta-analysis indicate that for many youth non-residential care is the preferred option, especially TFCO-A, both in terms of achievement of therapeutic objectives and cost-effectiveness (McCartney & Rosenthal, 2000).” TFCO-A = Treatment Foster Care Oregon for Adolescents
Kanine et al. (2015)	Maltreatment (mixed)	“Because day treatment provides mental health services to multiple children at a time in a classroom, it offers an opportunity to reach more children in one setting than individual or dyadic therapy. Furthermore, because evening or overnight expenses are not involved, day treatment costs are less than inpatient treatments while still offering many of the same services (Nyre et al. 2003).”
Bassuk et al. (2014)	Family homelessness	“Placing people who are homeless in supportive housing—affordable housing paired with supportive services such as onsite case management and referrals to community-based services—can lead to improved health, reduced hospital use, and decreased health care costs, especially when frequent users of health services are targeted. These benefits add to the undeniable human benefit of moving people from homelessness into housing”
Bee et al. (2014)	Parental mental health problems	“The lack of a cost-effectiveness model meant that it was not possible to quantify the value of collecting further information formally. However, conservative estimates suggest that between approximately 50% and 66% of people with SMI will be living with children under the age of 18 years¹¹ and that around 175,000 children provide informal care for a parent or sibling,⁵ almost one-third (29%) of whom will care for a relative with a mental health difficulty.⁶ It is likely then that there is potential value in developing interventions for this population and in the collection of good-quality evidence on their costs and effects. A cost-effectiveness model requires long-term outcomes, which, in this context, may include time in social care, mental health problems and other morbidity in childhood and adulthood. Therefore, as well as undertaking short-term trials to quantify the effect of interventions on child-centred QoL, cohort studies would likely also be of value to help map between these shorter-term measures and longer-term health and social-care outcomes.” SMI = serious mental illness; QoL = quality of life

Other researchers made recommendations or suggestions for exploration related to cost-effectiveness. For example, for parental mental health problems, Havinga and colleagues (2021) suggested exploring online interventions based on the premise that these interventions show high cost-effectiveness and acceptability. Elsewhere, Loechner and colleagues (2018) suggested that where resources are too scarce to provide time intensive interventions for the whole family, parenting skills could be incorporated into adult psychotherapy at little additional cost. This suggestion was based on a rationale that many of the prevention interventions reviewed included parental skills training and

reducing feelings of blame among parents. In addition, they suggested there may be a potential opportunity for relatively low cost intervention through brief psychoeducation information in the form of leaflets or lectures for families affected by parental depression.

Finally, Kinsey and Schlösser (2013) offered a cautionary warning about the pursuit of cheaper interventions; this was in relation to foster and kinship care interventions but may be a useful caveat more broadly when considering the balance of cost and effectiveness in the longer term:

“It may be that training is currently often delivered in a group format for economic reasons, as it is it [sic] cheaper to deliver group rather than individual interventions. However, as these groups seem to be ineffective, the cost is in fact wasted and families may go on to use further services (resources) regardless. It could be argued that resources could be saved by not running cheaper but ineffective groups and investing the money in more expensive individualized support. Research is required to ascertain if effective individualized approaches are more economical in the long-term (i.e. if the family then accesses fewer services/resources).” (Kinsey & Schlösser, 2013)

6.6.9 Intervention implementation: Barriers and enablers to successful implementation

Several barriers and enablers to successful implementation were highlighted in the included systematic reviews. Firstly, the importance of multi-agency collaboration was stressed, for example the need for seamless working between child and adult services (see for example, Bee et al., 2014). Barriers to intervention implementation included regular organisational restructuring, staffing shortages and staff turnover, and limited funding. Funding issues in particular were cited as a driver for treatment over prevention strategies. For example, Chen and colleagues (2021) found that limited funding was a reason for the tendency to focus directly on treating parents with schizophrenia, and not consider their children until they themselves were diagnosed with a mental illness.

High attrition rates were identified as a challenge, in part due to the complexity of the lives of some of these young people and their families (e.g. placement disruptions, and entering the care system or relocating mid-intervention) (see for example, Bee et al., 2014; Calhoun et al., 2015; Kerr & Cossar, 2014). Moreover, short foster placements were cited as a challenge, both for foster parents and foster children; foster parents may be reluctant to form deep bonds with the child, and the child may feel little permanence or certainty about the future (Van Andel et al., 2014). This in turn could impact initial participation, engagement or commitment to interventions.

For interventions with parents in prison, Troy and colleagues (2018) noted a particular problem with the transient nature of the prison population and a lack of parent-child contact. There was an inability to predict prisoners' release dates, which posed a major challenge for recruitment and retention. Similarly, the high turnover and transfer of prisoners made programme evaluation challenging, and recipients reported feeling "let down" by constant changes to the group. Finally, the most frequently reported barrier in this systematic review of prison populations was the lack of parent-child contact and the detrimental impact this had on opportunities for rehearsing and building skills learnt in the intervention, in particular parenting programmes. Due to these challenges, it was suggested that the traditional method of delivering parenting programmes where each session builds on the previous may not be best practice in the prison context. Stand-alone sessions were discussed as a means of increasing engagement and retention, but it was noted this may have unintended consequences, such as encouraging parents to opt out of sessions which could dilute the programme's intensity and cause group instability.

For interventions with runaway or homeless young people, fragmented service provision was frequently cited by young people as a barrier to engagement (Slesnick et al., 2009). Furthermore, a fear or lack of trust regarding violations of confidentiality and being returned home or to foster care acted as a barrier to many seeking services. Moreover, the likelihood of young people turning down services increased when their needs and goals did not match those of the service providers. A suggested solution was integrated interventions which addressed the range of needs of young people through one service provider, instead of linking young people to different services to meet their needs in parallel. This was posited to be particularly potent for young people because they tend to have fewer resources and less power than adults, by virtue of their age and developmental status. Integrated services were also highlighted as a strategy for supporting infants of mothers who misuse substances (Niccols et al., 2012), as these women reported difficulties using conventional systems of care (for reasons such as fear of losing custody, guilt, stigma, and lack of transportation) and requested a caring "one-stop" setting. As such, comprehensive and integrated services which address the needs of both women and their children are likely to be more successful (e.g. those that include on-site pregnancy-, parenting-, or child-related services with addiction services).

It was noted that a continuing cycle of evaluation and monitoring should occur, with routines created to facilitate this process; professionals may not be familiar or trained in evaluation methods, and this issue may be exacerbated in small authorities (see for example, SBU Assessments, 2017). One major challenge to implementation was the ethical quandary that arises when rigorous research evidence

and qualitative assessments of interventions are sparse, making it hard to make recommendations about whether or not to implement an intervention given the equivocal evidence (Bee et al., 2014; Bergström et al., 2020). Implementation science principles were one suggestion of how to implement evidence-based practices in public health, whilst mitigating against pitfalls (Bailey et al., 2018). James and colleagues (2013) discussed the institutional climate as both an enabler and barrier to successful implementation of evidence-based practice; they highlighted the need for organisational “buy-in”, collaborative implementation teams, and opinion leaders to introduce the intervention to the team. Finally, they noted that carefully planned and gradually phased in interventions may be more successful at gaining staff acceptance and buy-in.

To facilitate successful implementation, comprehensive intervention descriptions were noted to be important, as were treatment manuals, to aid treatment fidelity. For example, Montgomery and colleagues (2009) reflected that several of the evidence-based interventions they reviewed (e.g. Parent Child Interaction Therapy, Incredible Years, Treatment Foster Care, child-parent CBT) could be delivered by practitioners in a range of settings because they were manualised, with a clear training and supervision scheme in place. In fact, the parent training and treatment foster care interventions had been tested in different populations and settings, with generally consistent results. Fidelity to treatment protocols, investment in high quality training, and systems for ongoing supervision and quality control were highlighted as crucial here. Relatedly, Havinga and colleagues (2021) highlighted that greater efforts should be made to describe preventive interventions to enable them to be easily implemented by practitioners. They recommended the newly developed TIDieR checklist (Template of Intervention Description and Replication) as a tool to facilitate meaningful descriptions of interventions.

In addition, the intervention setting was cited by various studies as an important enabler for successful implementation. For example, Piegeschke and colleagues (2019) noted that schools may be a helpful setting for interventions for refugee children because school is a familiar environment, which may reduce the risk of stigmatisation and the fear that psychotherapeutic intervention may hinder their asylum process. For this same group of young people, O’Higgins and colleagues (2018) reflected that enthusiasm for interventions could be hindered by confusion about entitlements and language barriers.

Specific intervention characteristics could also aid successful implementation. For children exposed to domestic violence, Howarth and colleagues (2016) found that a sex balance in the children's groups was important to children and they also valued attending separate groups from their siblings.

Reducing the stigma associated with interventions was an oft-cited area for enhanced implementation efforts. Bee and colleagues (2014) wrote that from the limited qualitative data available, the acceptability of community-based interventions for parents with severe depression could be increased by including group-based activities and/or normalising components which were targeted at reducing parents' sense of social isolation and stigma. Relatedly, establishing trusting and non-judgemental relationships, where intervention providers saw participants as parents not patients, was suggested as key in adult-orientated interventions. As with the example earlier from Piegenschke and colleagues (2019), Bee and colleagues (2014) suggested making use of contexts that are most embedded within family routines, such as schools, community centres and patients' own homes.

6.7 Discussion

This Discussion section is structured as follows:

- An overview of the findings about intervention effectiveness, study quality, and research designs;
- How the findings compare to the Lester team's review and wider literature;
- Strengths and limitations of the present review;
- Implications for practice.

6.7.1 What was found

6.7.1.1 *Intervention effectiveness*

To summarise, this umbrella review systematically brought together secondary prevention and early intervention for young people who had experienced a wide range of adversities. The review included 14 years of research from six research databases and three grey literature sources, resulting in the inclusion of 82 systematic reviews and meta-analyses. This built on an existing independent umbrella review by Lester and colleagues (Lester et al., 2019; Lorenc et al., 2020), making some important alterations to their review, including increasing the age range from 3-18 years to 0-25 years, honing in on mental health outcomes specifically, removing language restrictions from the searches, and including insights from papers regardless of their AMSTAR 2 rating (in recognition of the valuable evidence from sources other than traditional 'gold standard' methodologies). For example, some ACEs

like experience of child protective services do not naturally lend themselves to randomised controlled trials or other traditionally valued research methodologies.

By organising the findings by ACE exposure, it was possible to explore which interventions might be particularly relevant based on part of the lived experience of young people, taking a needs-informed approach. This review found a wide variety of effective or potentially promising interventions for:

- Abuse and neglect (based on 12 reviews, with a median quality rating of 5/14);
- Displacement or being a refugee (based on just 4 reviews, with a median quality rating of 8/14);
- Parent or guardian mental health problems (based on 18 reviews, with a median quality rating of 8.75/14);
- Parent or guardian substance misuse (based on 6 reviews, with a median quality rating of just 3/14);
- Bereavement i.e. death of a parent or close relative (based on just 4 reviews, with a median quality rating of just 4/14);
- Involvement with child protective services (CPS) or living in care (based on 28 reviews, with a median quality rating of 6.5/14).

Typically, more inconclusive or mixed results were found for the following ACEs:

- Homelessness (based on 6 reviews, with a median quality rating of 7/14);
- Parental imprisonment or probation (based on just 2 reviews, with a median quality rating of 5.75/14);
- Parental separation or divorce (based on just 2 reviews, with a median quality rating of just 2.75/14).

As can be seen, there was a scarcity of literature on ‘parental imprisonment or probation’ and ‘parental separation or divorce’. The lack of systematic reviews on the former is somewhat surprising for a number of reasons, including the obvious disruptive nature of imprisonment, the fact that these parents are known to services (by virtue of imprisonment) thus their children may be relatively easily identified for enhanced support, and the fact that parents in prison are literally a ‘captive audience’ with significant time available, so may be somewhat amenable to intervention (though power imbalance and motivations for participation are an obvious ethical consideration here). The lack of systematic reviews on the latter is perhaps less surprising, as many families navigate separation or divorce with relative ease and without negative consequences, and for many it is not an ACE (i.e. not

adverse). There were also notably fewer than five systematic reviews on ‘displacement or being a refugee’ and ‘bereavement i.e. loss of a parent or close relative’, both of which ACEs offer a possible early intervention point for potentially at risk young people.

6.7.1.2 Study quality and research designs

Another finding was the considerable number of generally high quality systematic reviews on parental mental health problems (n=18) and on involvement with child protective services (CPS) or living in care (n=28), with median quality ratings of 8.75 and 6.5 out of 14, respectively. Moreover, traditionally well-regarded study designs featured in these often complex settings, including RCTs and non-randomised controlled studies. There was clear evidence that rigorous research can be carried out in challenging settings, including in out-of-home care. In addition to these traditionally accepted methods, researchers had conducted studies in settings that were not readily conducive to such designs. Other methods such as qualitative or mixed method approaches such as focus groups and interviews, and service evaluations featured in the systematic reviews. These mixed method approaches seem important to ensure effectiveness is understood alongside other crucial elements such as acceptability and process factors. Interventions for ACEs such as homelessness, displacement, and/or refugee status were, at times, markedly quite responsive and flexible, opportunistically providing interventions to young people. This creativity and responsiveness is a valuable approach to engaging with young people who have experienced adversity, as it allows you to meet young people where they are at, as well as promoting young people’s agency, autonomy and choice.

6.7.1.3 Findings of the present review compared to Lester and colleagues’ review and the wider literature

In their earlier umbrella review, Lester and colleagues (Lester et al., 2019), found 98 reviews which met their criteria; this number was reduced down to 31 meeting their quality threshold for inclusion in their best evidence synthesis. Lester and colleagues found the most evidence on looked-after children and sexually abused children. The former finding was replicated in the present review, but the latter finding was not, with the present review finding just two studies where the primary ACE was sexual abuse. Other papers could have included young people who were sexually abused, and the most likely instances of this would be in the remaining 10 papers in the ‘Abuse and Neglect’ category and the 28 papers on ‘Involvement with Child Protective Services (CPS) or Living in Care’ as young people could have experienced a number of ACEs preceding CPS involvement. As opposed to sexual abuse, ‘parent or guardian mental health problems’ was the second most common ACE exposure in the present review. This could have been as a result of our narrower focus on prevention and early

intervention for mental health, excluding treatment. It could also have been due to the expanded age coverage compared to Lester and colleagues (from 0-25 years, instead of 3-18 years). With this expanded age criterion, we found a number of interventions to support perinatal mental health problems in particular, such as post-partum depression, which would have likely been excluded with narrower age criteria. This is an important finding given the prevalence of perinatal mental health problems (O'Hara & Wisner, 2014), and what is known about the importance of parental attachment figures and supporting bonding (Ainsworth, 1978; Bowlby, 1969; Graham, Blissett, Antoniou, Zeegers, & McCleery, 2018; C. Hughes, Devine, Mesman, & Blair, 2020), as well as the developmental importance of the first 1,000 or so days (HM Government, 2021; House of Commons: Health and Social Care Committee, 2019). Government services are also recognising this important stage, with recent NHS changes to provide and enhance perinatal mental health service provision (Mental Health Taskforce, 2016).

In addition, our stricter focus on young people's mental health outcomes specifically, rather than broader outcomes including criminality and homelessness (as Lester and colleagues used), ensured this review could provide sufficient detail on young people's mental health. Although the other outcomes are clearly important, this decision was an informed and pragmatic one, predominantly because mental health problems are a highly prevalent (and possibly increasing) issue for young people (Newlove-Delgado et al., 2022), and mental health problems remain among the top ten leading causes of disease burden worldwide (Arias et al., 2022; GBD 2019 Mental Health Disorders Collaborators, 2022). Exclusively focusing on mental health outcomes was also a congruent decision to fit into the wider programme of work by the Timely team to develop early identification tools for young people's mental health problems; this review provides the foundation for next steps to intervene early if young people with specific risk factors, namely ACEs, can indeed be identified earlier for proactive and proportionate support.

By removing the quality assessment inclusion threshold set by Lester and colleagues (2019), this review was able to identify and include additional papers on ACEs which had a particular dearth of reviews, such as parental imprisonment or probation, bereavement, and parental separation or divorce. Whilst Lester and colleagues included just one review for each of these ACEs in their best evidence synthesis, our review included insights from two, four and two reviews respectively.

Moreover, Lester's team chose to group their review findings by intervention type which meant that their results were described predominantly in terms of which ACEs were treated with given

interventions, and what the effectiveness was for said intervention from the highest rated reviews. However, in the present review, I wanted to understand what different interventions were available for specific ACEs and how effective these were when used in this ACE-led way. By taking an ACE-orientated approach, instead of an intervention-orientated approach, it was possible to understand the wide variety of interventions tried and tested for different types of ACEs, rather than focusing in on typically used ones such as CBT. Through this ACE-orientated approach, detail was not lost from the more eclectic or non-traditional interventions, such as dance, yoga, bibliotherapy, active science sessions and support camps. In contrast, some of the nuance of these interventions was lost through Lester's team's groupings as many interventions would fall into the broad category of 'psychological therapies other than CBT', 'Interventions aimed at parents' or 'Cross-sector support (for example, case management)'. Lester and colleagues' approach raised a few problems for me, as described below, hence opting for a different approach. These problems were:

- 1) The systematic reviews included in the umbrella review often contained a number of different interventions so would have to be distilled down to the best fit, which begs the question of what to do when the systematic review was not written in this way and combines interventions.
- 2) Interventions in the real-world often do not neatly or meaningfully package into domains such as CBT, therapies other than CBT, psychoeducation etc. Psychological interventions, for example, often share a common thread (Wampold, 2015) and therapists in more complex cases will often use their expertise to fit the intervention modality to the person in front of them (Barton & Armstrong, 2018; Stewart, Chambless, & Stirman, 2018). Besides this, interventions often overlap; for example, CBT will almost always contain 'psychoeducation', and Lester and colleagues' category of 'parent and foster carer training' may also have included CBT or other psychological therapy modalities, as was found in the present review. As such, these intervention categories lose utility.
- 3) Perhaps most importantly, the present review aimed to identify which interventions could be offered when a young person presents with exposure to a given ACE; thus, taking an ACE-led approach best answered this question of what to do in a real-world setting.

Encouragingly, this ACE-led, rather than intervention-led approach, has also been used by other teams (such as Bellis et al., 2023), with broadly similar clusters of interventions and intervention targets (e.g. child, parent, mother specifically etc). Bellis and colleagues, working alongside the World Health Organisation (WHO) and Public Health Wales, amongst other organisations, targeted similar ACEs to the present review, and identified largely similar interventions to mitigate poor mental health

outcomes, including working with parents to develop safe and stable relationships, and provision of services which are trauma-informed and aware of the impact of toxic stress.

6.7.2 Strengths and limitations

This umbrella review had many strengths, as well as some limitations, as outlined below. Firstly, a major strength of the review was its comprehensiveness and clear focus. In this review, over a decade of literature was covered, resulting in over 80 systematic reviews and meta-analyses (made up of hundreds of primary studies), and a wide array of ACE types and intervention types. Furthermore, used with permission from the Lester team (Lester et al., 2019; Lorenc et al., 2020), the search strategy for this review was very comprehensive, with over sixty lines of searches, and particular detail around synonyms for each ACE type. This was also supplemented with reference searches and grey literature searches, leading to the inclusion of relevant theses and articles. This comprehensive and triangulated approach increased the chance that all relevant literature was identified in the searches.

In an effort to minimise in-built racial bias (Knight et al., 2021) and a Western bias in paper selection, and at the recommendation of a medical school librarian, language limits were not set for this review, unlike many reviews. Consequently, the analysis included a German review (Piegenschke et al., 2019) in the final collection of systematic reviews, and we screened out a number of papers that did not meet criteria in languages such as Spanish, German, Arabic and Chinese. As such, we can be quite confident no published paper was screened out based on the language of the authors, albeit publication bias is likely to remain. Furthermore, the team was composed of people from a mix of ethnic backgrounds, as well as different disciplines, including psychology, social work, medicine, and the third sector, which brought a valuable breadth of personal and professional expertise. However, through circumstance rather than design, we were an exclusively female team, so lacked diversity in this respect.

Throughout the review process, we were informed by accepted frameworks and guidance for carrying out systematic research (Moher et al., 2009; Popay et al., 2006; Shamseer, Moher, Clarke, Ghera, Liberati, Petticrew, Shekelle, & Stewart, 2015; Shea et al., 2017a). This included following PRISMA guidance for both protocols and systematic reviews, pre-registration of the study protocol, quality appraisal using an established tool, and following guidance on narrative synthesis of findings. I also learnt from medical school training sessions and from exploration of other umbrella reviews to guide my approach to leading the team during this work and sought advice from academics with expertise in umbrella reviews. All of these efforts should increase the robustness and replicability of this work.

The main limitation of this review was finding a method to clearly yet accurately comment on the effectiveness of interventions. It was a considerable challenge to condense many different findings from many primary sources and heterogeneous outcome variables into a meaningful summary of effectiveness for mental health outcomes. I opted to narratively summarise this based on the original authors' conclusions and visually display this in summary tables as a RAG rating in order to facilitate understanding. However, this RAG rating was a crude rating scale which provided a broad-brush picture of the umbrella reviews' findings, rather than a standardised approach to effectiveness. As such, it is intended for this to be used alongside the narrative descriptions, and more specific detail should be sought from the original systematic reviews themselves. The aim of an umbrella review is to summarise vast amounts of data and distil it into a meaningful response to the research question (Choi & Kang, 2023), and though imperfect, this crude approach seemed like a reasonable way to do so. Moreover, this approach was similar to the Lester team's approach, so there was precedent for such a method, though Lester and colleagues gave their rating based on findings from the single most reliable review.

In addition, a clear caveat in the results presentation is that ACEs often overlap and cluster, with young people being at heightened risk of subsequent exposure following exposure to a single ACE (for example, see Giano, Wheeler, & Hubach, 2020; Lacey, Howe, Kelly-Irving, Bartley, & Kelly, 2020). To aid understanding, for this evidence synthesis, the findings were grouped into categories based on the 'primary ACE' as implied by the authors in the systematic review. However, some ACE categories notably overlapped. For example, most of the young people in the category of 'Involvement with Child Protective Services (CPS) or Living in Care' would have appropriately also fit into the category of 'Abuse and Neglect'. Had a different grouping method been chosen, the interventions would have clustered somewhat differently, and the final conclusions may have differed. However, this approach seemed appropriate for a number of reasons: 1) it provided a more understandable synthesis of the evidence; 2) the interventions in each category had relative coherence e.g. foster parent training and attachment-based interventions for young people involved with CPS, and shelter drop-in interventions for homeless young people; 3) the approach was needs-led and child-centred, revealing patterns of interventions that matched population needs, as intended by this thesis.

Not only do ACEs overlap, but inevitably so did the populations of some of the systematic reviews, with multiple papers being published from some research groups (e.g. follow-up studies) or less obviously, with the same young people potentially being invited to participate in interventions by

different teams due to their ACE exposure. It was decided not to correct for this as it would not be possible to effectively address these issues. However, it is important to note that each systematic review (and subsequent results) may not necessarily be an independent data point. The latter issue at least is likely to be reflective of scenarios which play out in actual service provision, whereby some young people are known to services and offered multiple interventions, so any impact is not entirely attributable to a single intervention.

There were limitations associated with the chosen methodology of an umbrella review specifically. The overview nature meant there was little available information on some of the secondary research questions, for example, regarding cohort identification methods and intervention cost-effectiveness. It was unclear whether there was a true evidence gap, or if the present review's methodology was simply too high-level to capture relevant information. It may be that information relating to secondary research questions would be available in primary studies. As such, the information on secondary questions here should be taken as highlights, and not a definitive systematic conclusion on these areas. If these questions were of particular interest, specific scoping reviews might provide more detail. Though this is a limitation, an umbrella review appeared to be an appropriate method for the primary research question on effectiveness of interventions given the vast quantity of systematic reviews available on secondary prevention of ACEs.

Finally, both a strength and limitation of the approach to the results presentation was the focus purely on mental health. This was appropriate to address the research questions and meant that effectiveness for different outcomes was not conflated, as the effectiveness of interventions was purely presented in terms of young people's mental health outcomes. However, it is worth noting that interventions may be effective or ineffective for mental health problems (including substance use), yet have differing results for other important outcomes such as education, homelessness, or criminality. When selecting interventions for young people who have been exposed to ACEs, this caveat should be borne in mind. Though an intervention may be indicated for one outcome, it may be contraindicated for another, and the specific service context or drivers for intervention should be considered too.

6.7.3 Implications for practice

By compiling the interventions by ACE type, it was possible to identify interventions that might align with the specific needs of young people. This review highlighted relatively consistently recommended interventions for young people involved with CPS, such as the ABC programme, Incredible Years

programme and other foster parent training programmes, and various therapeutic modalities for young people who had experienced abuse or neglect. However, it also highlighted an evidence gap for professionals working with young people who are distressed by experiences of displacement or refugee status, parental death, parental incarceration, and parental separation or divorce. In these instances, it might be prudent to borrow evidence from the closest matching ACEs or experiences.

The present review specified that the child did not need to be the intervention target and thus, contextualised the child within a wider support system, including parents and caregivers, wider family, school, and other professional services. By adopting this wider inclusion remit, it became clear that interventions could help young people's mental health by taking a systemic approach, rather than solely targeting the young person themselves. For example, many interventions took a proactive approach to a child's mental health by treating parental mental health problems or substance use, or by training new foster parents in attachment-based methods. This has the benefit of supporting multiple people directly and indirectly through intervention (i.e. parent, child(ren), partners, other family members), as well as being a practical way of mitigating certain ACEs, because although a child may not be known to services, their parents may be through the ACE itself (e.g. their mental health difficulties). Moreover, there were examples of trauma-informed service delivery models, such as the Children's Advocacy Centre (CAC) model, which sought to promote young people's mental health outcomes through the organisation's culture and practices. This finding is unlikely to be surprising to disciplines such as social work that have a long history of working with the family unit, not just the target individual.

Another finding which will not be surprising to clinical and care professionals was the value of multi-agency, joined up working, and flexible and responsive services, exemplified in ACEs such as sexual abuse and homelessness. Moreover, barriers to successful implementation of interventions unsurprisingly included staff shortages and high turnover, and insufficient and/or short-sighted funding provision. Intervention attrition was a considerable challenge, especially in settings where it was unclear how long an individual would be there (such as out-of-home care and prison). A modular approach to interventions may provide a valuable avenue for exploration to address this. However, it should be noted that building a trusting and secure environment in these settings is vital, and short components of interventions may not provide the secure environment needed to see benefits, so this would need further evaluation.

Where interventions were effectively implemented, there were often detailed intervention manuals and comprehensive training, plus ongoing supervision to maintain intervention fidelity. Moreover, there were ongoing evaluation efforts to sustain rigour, as well as pragmatic approaches to working with target individuals. These included co-location of interventions, a focus on stigma reduction, and creative and proactive engagement efforts.

Finally, the review identified a few different methods for detecting young people who may be eligible for intervention, for example, using screening tools for young people directly or for their parents or caregivers. Notably, only one systematic review mentioned the use of data-driven analytic approaches to identify young people, and the specifics of this were not well-detailed. As such, there may be a gap for identification methods which harness administrative data to identify cohorts for intervention.

6.8 Conclusions

This umbrella review identified a huge array of interventions to prevent or intervene early following ACE exposure, and mitigate poor mental health outcomes in young people. It highlighted where the most evidence lies and where there is a comparative dearth of literature, and scope for further research. In addition to exploring effectiveness, it also highlighted barriers and enablers to implementation of interventions, costs and unintended consequences of intervention, modifications and targeting of interventions, methods of identifying eligible cohorts, and some limited cost-effectiveness information.

The review fits within a wider piece of work on early identification. The chosen method of synthesising interventions by ACE type provides part of a plausible care pathway involving early identification models which identify at-risk young people, and then with this review pointing to worthwhile early interventions to address risk factors for mental health problems, namely specific ACEs.

Finally, this review aligned with the direction of travel of mental health advocacy organisations which are calling for increased prevention and early intervention, enhanced use of data, cross-sector collaboration, and a public health strategy for mitigating the impact of adverse experiences in childhood (All Party Parliamentary Group on a Fit and Healthy Childhood, 2024; Bellis et al., 2023; Children's Commissioner, 2023; Doughty, 2024). As illustrated here, many prevention and early intervention strategies exist, are known about and have been well-researched. The key step is to offer these to young people who need them most.

7 Chapter 7: Discussion and Conclusions

7.1 Chapter overview

This chapter summarises and synthesises the findings from each of the studies within this PhD, drawing conclusions about how an understanding of the prevalence and impact of ACEs can help to target mental health resources. Most of the chapter is structured by the research questions posed at the beginning of this thesis, starting with the chapter-specific research questions, followed by conclusions regarding the overarching research questions of this PhD. The chapter ends with a discussion of the strengths and limitations of the thesis, recommendations for potential areas of future work, and concluding remarks.

7.2 Summary of findings

This thesis aimed to explore whether resources to support young people's mental health and wellbeing could be usefully targeted by taking an ACE-informed approach. Specifically, by understanding the prevalence and impact of different ACEs on young people's mental health outcomes, and exploring interventions which may mitigate detrimental impacts of ACE exposure.

Below, the findings from the thesis are synthesised in relation to the research questions posed in Chapter 2. These cover:

- 1) Prediction of young people's mental health problems;
- 2) Measurement of ACEs;
- 3) Intervening following exposure to ACEs.

7.2.1 Prediction of young people's mental health problems:

7.2.1.1 How important are ACEs in the prediction or early identification of young people's mental health problems?

Through a rapid literature review and Delphi survey involving a panel of experts, I learned that experts in childhood mental health view many, though not all ACEs, as potentially highly predictive of mental health problems. ACEs such as 'being a looked after child (LAC)', 'sexual abuse', 'domestic violence' and 'emotional neglect', amongst others, were all rated as highly predictive by a small panel of experts in children's health and wellbeing. Conversely, the factor of 'primary caregiver(s) marital status' which could be a proxy for the ACE of parental separation or divorce was ranked lowest (out of 106 factors)

within the 'Social and Environmental' domain. As societal norms around separation change, this experience may no longer be viewed as important when it historically was seen as such, and perhaps literature on ACEs has not caught up with this cultural shift yet. When defining ACEs, I did consider whether to omit parental separation or divorce from the definition due to the contentiousness around its inclusion, its possible qualitative difference from other ACEs, and the fact many of us experience this with neutral or even positive outcomes. However, its inclusion was driven by published literature and the fact that a significant portion of young people do report this experience as a challenging one, at least in the short term (Arkowitz & Lilienfeld, 2023; Vederhus, Haugland, & Timko, 2022).

7.2.1.2 Where do ACEs fit in the context of other important risk factors for young people's mental health problems?

ACEs were not the only risk factors ranked as highly predictive, and it is likely that an accurate risk prediction model might need to include other variables such as 'school exclusions', 'severe health condition', 'sex (biological)', 'repeat hospitalisation', 'nutritional deficits' and 'neuro-developmental conditions (e.g. autism)', if it is to identify young people at risk of mental health problems earlier. Some of these risk factors are likely to be more easily measurable using routine data than others. Some are sporadically collected, but might have inherent collection bias; for example, 'heavy alcohol use' whereby alcohol use information is predominantly collected when this is already identified as a problem (such as by a GP). Others, such as 'poor sleep patterns' are not generally part of routinely-collected structured data but may be possible to capture by supplementing data with wearable technology data, or using large language models (LLMs) to facilitate interrogation of unstructured data. Furthermore, some are challenging to define and operationalise, let alone measure in routine data, such as 'lack of supportive relationship(s) with a trusted adult', 'poor primary caregiver-caregiver relationship' and 'poor peer relationships'. For these, self-reported outcomes may be of value, though could significantly limit the scalability of any prediction models using these risk factors. That said, QRISK2 is a commonly used prediction tool in the NHS and is dependent on self-reported values (Hippisley-Cox et al., 2008), so scalability could be improved by allowing people to input measures into the tool themselves. The decision-making process of whether to extract, measure and include factors in risk prediction models is about weighing up the trade-offs of resource and time-investment versus predictive utility. Largely, it is impossible to know each risk factor's actual predictive utility until this is tested. However, the Delphi framework provided expert opinions on a starting point for where to consider directing data extraction and measurement efforts when developing risk prediction models. This will be especially useful for data scientists to develop risk prediction models. They tend not to

have clinical experience themselves, thus the Delphi process and framework development facilitates expert-informed direction in this endeavour.

Interestingly, some of the highly ranked risk factors were not included in this thesis's definition of ACEs but could legitimately be. For example, they could be captured under physical illness of the young person themselves or physical illness of their parent or caregiver (e.g. 'traumatic brain injury' and 'severe health condition' relating to the young person directly, and 'primary caregiver(s) chronic (long lasting) illness' and 'severe illness in family' relating to their caregiver). This does highlight an interesting potential limitation in the definition used. Specifically, experts viewed these experiences as important for mental health outcomes, and they may actually reflect adverse childhood experiences if a proven causal relationship was found between them and poor mental health. However, their exclusion from the thesis definition was largely a pragmatic decision to follow accepted literature, leading to a definition which was broad enough to have good coverage, but narrow enough to give practical scope for exploration. I decided not to include young people's physical health problems as an ACE, because if I had it would feel inappropriate not to also include mental health problems (for parity of esteem), yet this would result in an oddity where poor mental health was both an ACE and also the outcome of interest in this thesis. The literature I read during development of the definition of ACEs tended to include parental mental health problems as an ACE, but not parental physical health problems. Perhaps this distinction is a historical one relating to social stigma around mental health, a lack of understanding about the possible impact of parental physical health on young people's mental health, or perhaps may be reflective of a genuine difference in impact. It seems important to me that the definition of ACEs remains a useful and meaningful grouping, and does not become too expansive and a tautology whereby any experience that is adverse becomes an ACE, when research into ACEs often seeks to understand outcomes following ACEs.

7.2.2 Measurement of ACEs:

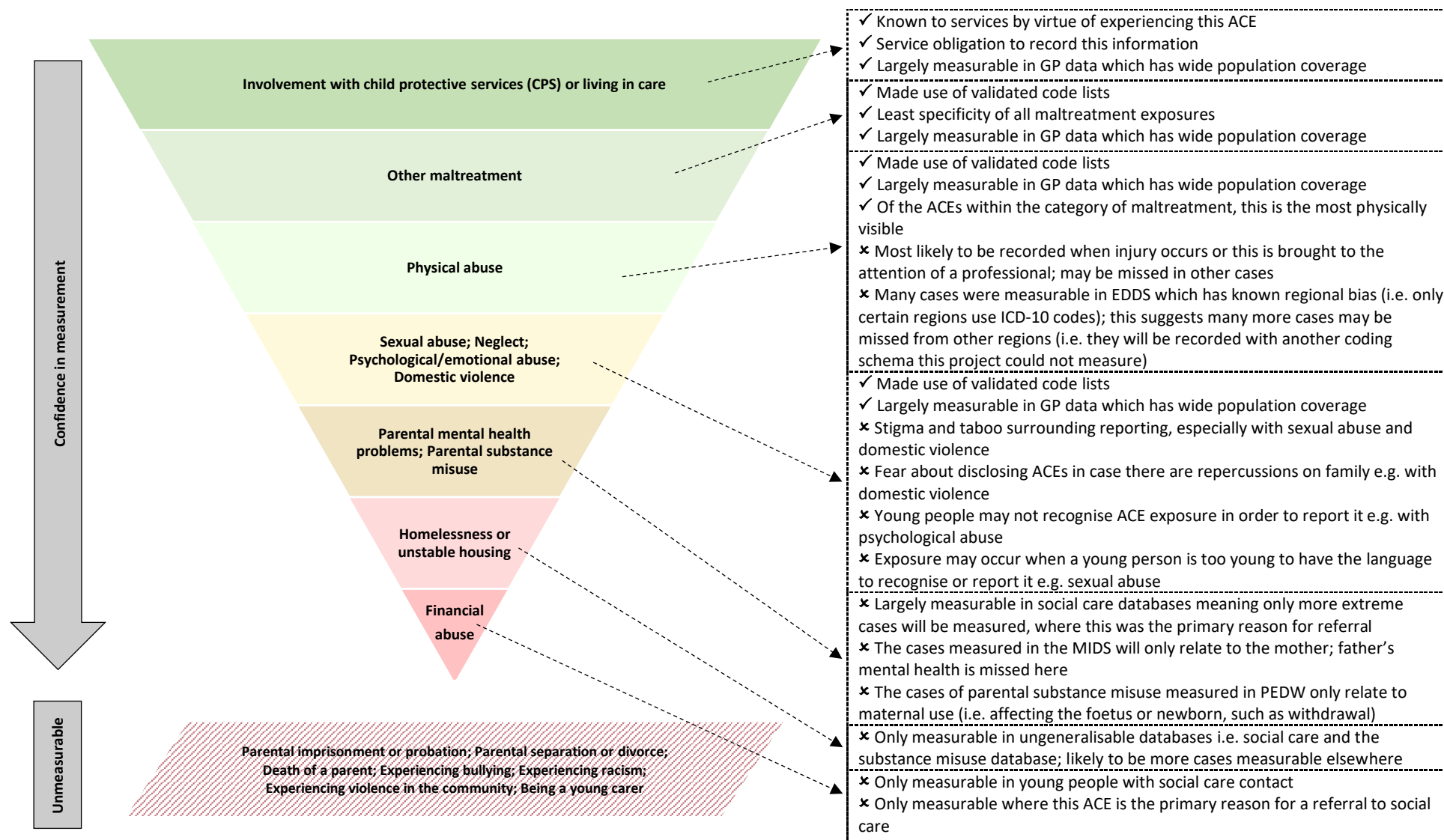
7.2.2.1 *According to routine data sources alone, what is the prevalence of ACE exposure in a geographically bound population of young people? How frequently are different ACEs recorded in routinely-collected data sources?*

Through a study of routinely-collected linked data using the Secure Anonymised Information Linkage (SAIL) Databank, I learned about the prevalence of different ACEs within the population of Wales, UK, according to electronic record data. From a cohort of 1,113,776 young people who were aged 0 to 17 years between 1 January 2013 and 31 March 2020, a total of 15.14% (n=168,660) had a recorded experience of at least one ACE from the list defined in this thesis. This ACE prevalence broke down

into 7.14% (n=79,490) girls, 8.01% (n=89,166) boys, and <0.00% (n=4) of unknown sex. This was compared to a baseline cohort which comprised 548,673 girls (49.26%), 565,086 boys (50.74%) and 17 people of unknown sex (<0.00%). This means that of all the girls who could have had a recorded ACE, 14.49% did. Of all possible boys in the cohort, 15.78% had a recorded ACE. Finally, of all the people where sex was unknown, 23.53% had a recorded ACE.

Unsurprisingly, the frequency of ACE recordings depended on the type of ACE. As noted in Chapter 5, 'other maltreatment' was the most frequently recorded ACE in the routine data sources (9.9% of the baseline cohort), which represented a catch-all category for ACEs which could not clearly be distinguished as specific types of maltreatment. The second most frequently recorded ACE type was 'parent or guardian mental health problems', with 4.7% of the baseline cohort having a recorded experience of this ACE. 'Financial maltreatment' was the least frequently recorded ACE, with <0.001% of the baseline cohort having this ACE recorded. This variation in prevalence of each ACE type could have been for a number of reasons, and is likely to be a combination of the following: true differences in ACE prevalence based on ACE type; ability to recognise and record each ACE type; ability to measure each ACE type; and the database type in which an ACE was measured. As shown previously, Figure 23 represents an approximation of my confidence in the measurement of each ACE type, with reasons provided for differing degrees of confidence, including those just noted. The variation represents a major limitation of this study, and the findings of the study should be interpreted as a commentary on the recognition, recording and measurability of different ACEs, rather than representing the true prevalence of ACEs. For example, through this study it is possible to learn about the extent to which maltreatment is recorded in routine sources, which organisations detect it most or least, and how measurable maltreatment is in different sources, rather than representing an accurate number of all maltreatment cases. The actual number is likely to be far higher. However, the value in this study lies in the ability to detect a great many cases of ACE exposure through data which has already been collected, as opposed to collecting more data on young people who may have reported exposure to a number of professionals already, or had ACE exposure detected based on their presentation. This data could theoretically feed into early identification tools for young people's mental health, and help to determine the predictive utility of ACEs. If certain ACEs turn out to be predictive of mental health problems, then this could provide a mechanism for targeting early support in an ACE-informed way. This involves a number of 'ifs' and hypothesis testing must occur first to realise any possible potential of ACE-informed early identification tools.

Figure 23: Diagram to represent my approximate confidence in the measurement of each ACE type, with details of some reasons underlying the degree of confidence



7.2.2.2 Which, if any, ACEs are not measurable using routinely-collected data?

Certain ACEs were notably not measurable using the routine data sources I had access to, despite having access to a total of 18 routine sources (of which, 3 were demographic databases, 11 were healthcare, 3 were social care, and 1 was education). The following ACEs were not measurable within the 18 databases at my disposal: 1) a parent or guardian being in prison or on probation; 2) parental separation or divorce; 3) death of a parent or guardian; 4) experiencing bullying; 5) experiencing racism; 6) experiencing violence in the community; or 7) being a young carer. These ACEs are linked to poor mental health outcomes (M. Allen & Donkin, 2015; Arseneault, 2018; Felitti et al., 1998; The Philadelphia ACE Project, 2019; Van Niel et al., 2014), and the current routine data sources were not a feasible way to identify them. Other methods would be required to detect these ACEs and a number of avenues for exploration exist. One potential method includes linking newer routine data acquisitions within SAIL, for example, databases from the Ministry of Justice, such as the Data First Probation Dataset⁷ and CAF/CASS Wales⁸, which could offer options for measuring parental imprisonment or probation, and separation or divorce, respectively. Linkage of parents' records may also help with the measurement of some of these ACEs, in particular numbers 1 to 3 as these relate to parents.

7.2.2.3 Which routine data sources are the most and least helpful for the measurement of ACEs?

With regard to my research question about which data sources were the most and least helpful for measuring ACEs, the latter is much easier to answer than the former, though both are commented on below. The 'least helpful' data sources were the seven in which it was not possible to measure any cases of ACE exposure, namely:

- Demographics: baseline population database (WDSD); birth registry (ADBE);
- Education: education attainment and attendance (EDUW);
- Healthcare: NHS 111 call data (NHSO); outpatient referrals from primary care (OPRD); critical care (CCDS); pathology results reporting service (WRRS).

Of note, for all of the data sources noted above except the WRRS, no variable mapped to any ACEs, thus they were not measurable. In contrast, for WRRS, which used Read codes as its coding scheme, it was theoretically possible for ACEs to be measured, but zero cases were identified. This is hardly surprising as this database is for pathology requests and results (i.e. blood tests), and access to this database was predominantly sought to benefit the wider Timely project on young people's mental

⁷ <https://web.www.healthdatagateway.org/dataset/f93ffd0a-137a-4f90-98aa-dc2136397164>

⁸ <https://web.www.healthdatagateway.org/dataset/29a714e1-5289-4362-be24-2848c954344e>

health, rather than for ACE measurement. However, there was a remote possibility that a few of the confirmed and suspected maltreatment Read codes could have featured in this database such as ‘TL2.: assault by poisoning’ or ‘X85.: assault by drugs, medicaments and biological substances’.

Though two of the three demographic databases did not contain any recorded ACEs, these data sources were essential for cohort creation and characterisation. The Welsh Demographic Dataset (WDS) forms the backbone of every project in the SAIL Databank. Containing the unique IDs for the individuals in a cohort, other databases are linked to this by matching these IDs. The birth registry (ADBE) allows SAIL analysts to identify who has been born and should enter an electronic cohort. Similarly, the death registry (ADDE), in which seven cases of an ACE were recorded, makes it possible to see who has died, and thus left a cohort. Though seven cases is very few in a cohort of over 1.1 million young people, this provides important information about individuals who died tragically young with the cause of death recorded as an ACE, in this case by physical maltreatment.

Unexpectedly, no variables within the Pre-16 Education Attainment and Attendance Dataset (EDUW) mapped to ACEs defined in this thesis, meaning that this database did not contribute to the measurement of any ACEs. In spite of this, there is good reason to believe that this data source is useful when trying to identify mental health problems earlier, as is the aim of the Timely team. For example, using EDUW (which covers state-funded schools only), absenteeism and exclusions from school were shown to be associated with mental health problems, self-harm and neurodevelopmental conditions, potentially implicating school attendance as a predictor of poor mental health (albeit this could be a bidirectional relationship) (Ann John et al., 2022). In addition, other potential predictors of mental health problems identified through the Delphi study and thus useful to capture in early identification tools are included within EDUW, such as proxies for poverty and financial hardship (like free school meal eligibility), and also physical and neurodevelopmental conditions (like special educational needs and disabilities (SEND) status).

The NHS Hospital Outpatients Dataset (OPDW) only contained 34 recorded cases of ACEs (specifically ‘physical maltreatment’, ‘other maltreatment’, and ‘involvement with child protective services (CPS) or living in care’), within a database of 658,890 unique individuals. In addition, though the Emergency Department Dataset (EDDS) did identify a number of cases (8,287 cases within a total of 710,275 unique individuals, consisting of the ACEs ‘physical maltreatment’ and ‘other maltreatment’), on discussion with collaborators at the ADP who developed the maltreatment code lists, it became clear these cases were highly likely to involve significant geographical bias. Specifically, the ADP’s

maltreatment code lists were developed for use in GP data (WLGP) and patient episode data (PEDW) and they found it surprising that these captured so many cases within other databases like EDDS. For EDDS specifically, not all emergency departments across Wales use ICD-10 codes, instead using their own coding scheme, so the ADP noted that identification of cases in this database are likely to be department-dependent. As such, the cases identified help to get closer to the 'true' prevalence of the total number of ACEs in the population, and the number of cases of physical and 'other' maltreatment (reducing the measurement gap illustrated in Figure 12), but include inherent bias and would not be meaningful at a more local level (i.e. absence of cases in certain geographies as measured through the EDDS would not indicate a true absence of exposure).

The three social care databases were variably helpful depending on the underlying question within this thesis. In terms of understanding the total population exposure to at least one ACE, presence in these databases alone was almost synonymous with ACE-exposure so the database total was the only required information for this. For example, being present in the looked-after child database was akin to known exposure to at least one ACE. The exception to this was the database on children receiving care and support (CRCS), because a very small proportion of the young people in this database were present purely for other reasons, such as the presence of neurodevelopmental conditions like autism, which required care packages. However, when considering the types of ACEs experienced by young people, the specific variables within the social care databases were more useful, providing information on the categories of ACEs experienced, including the main reason for referral to social care. These databases provided information about a smaller but significant subpopulation who may have experienced the most extreme cases of adversity.

With regard to the question of the 'most helpful' data sources for the measurement of ACEs, this naturally depends on the type of ACE of interest. For example, parental mental health problems were solely measurable in two social care databases (CINW and CRCS) and the maternal indicators database (MIDS), and this was the second most prevalent ACE (with 52,385 out of a possible 1,113,776 exposed), behind only 'other maltreatment'. However, the GP database (WLGP) was probably the 'most helpful' for a number of reasons. WLGP captured the most cases of ACEs of any of the databases. Furthermore, it captured a breadth of types of ACEs, including physical maltreatment, sexual maltreatment, psychological maltreatment, neglect, other maltreatment, parent or guardian interpersonal violence, and involvement with child protective services (CPS) or living in care. Finally, and possibly most importantly, the general practice database was one of the databases with the greatest coverage of the population (comprising 946,753 young people, of which 49.38% were girls,

50.62% boys, and <0.00% were of unknown sex). Alongside the education database, it is likely to be the most representative sample. Though there are barriers for some people to access the GP (Corscadden et al., 2018), a referral is not needed to visit the GP and many young people have routine contact with a general practitioner. Thus, the reach and representativeness of this database is likely to be a great strength when measuring ACEs. Relatedly, using the Clinical Practice Research Datalink (CPRD), Syed and colleagues found GP data vital for measuring indicators of ACEs, with over 70% of ACEs detected in their study via maternal EHRs and in GP data (Syed et al., 2022). Of note, the present study using the SAIL Databank did not link parental records with young people's due to time, cost, and data minimisation principles. This would be a valuable avenue for future exploration as maternal records have proven helpful in ACE measurement in other studies like that of Syed and colleagues' (2022).

7.2.2.4 What, if any, value is added by linking multi-agency data compared to using single-agency data for the measurement of ACEs?

Finally, with respect to the research question about the value of data linkage when measuring ACEs, it was clear how valuable multi-agency linked data were. The single database with the greatest population reach and also the largest number of young people to have experienced an ACE was the GP database (WLGP) with 102,090 people experiencing at least one ACE (9.2% of the baseline cohort). That is, just under two thirds (60.5%) of the young people who had been exposed to an ACE could be identified using GP data alone (102,090 of 168,660 cases). However, a further third (39.5%) of young people who had experienced one or more ACEs were detected by linking data together. That is, 66,570 young people would not have been identified if data from General Practice was solely relied upon. Moreover, some types of adversity which were not measurable using young people's GP data were measurable in other data sources, specifically parent or guardian mental health problems or substance misuse, and homelessness or unstable housing. If early identification tools for young people's mental health are to be developed, much can be gained from linking data from other data sources to provide a somewhat more holistic picture of a young person's life. Lastly, it is worth noting that GP data are not truly single-agency data anyway, and anyone hoping to explore topics across different practices would currently need data sharing agreements with each practice. Therefore, it was only possible to measure so many ACEs because data from different practices were brought together into a single database. Progress has been made in this area, spurred on by the coronavirus pandemic, in which a large national team developed the OpenSAFELY platform (see for example, Andrews et al., 2022), facilitating analysis of GP data in England. However, at present this only has ethical approval to be

used for research relating to COVID-19. Data linkage was of great value to the present thesis, facilitating the measurement of more, as well as different, ACEs across a wider population.

7.2.3 Intervening following exposure to ACEs:

7.2.3.1 *What is the evidence base on intervention effectiveness for preventing or intervening early to support children and young people's mental health following exposure to ACEs?*

Through an umbrella review update which spanned 14 years of research from 2007 to 2021, explored six research databases and three grey literature sources, and resulted in the synthesis of 82 systematic reviews and meta-analyses, I was able to better understand the evidence base on interventions for young people's mental health after exposure to a variety of ACEs. The review took a needs-informed approach, with the findings being structured by ACE type to ensure that if we can identify young people earlier who may benefit from additional support, we are clearer on what types of support might match their needs.

This review found a wide variety of effective or potentially promising interventions for the following ACEs (organised in descending order in terms of the number of reviews on each ACE category):

- involvement with child protective service (CPS) or living in care;
- parent or guardian mental health problems;
- abuse and neglect;
- parent or guardian substance misuse;
- displacement or being a refugee;
- bereavement i.e. death of a parent or close relative.

Interventions included psychoeducation and psychological interventions, such as trauma-informed care, cognitive-behavioural-based interventions and couples therapy (for parents), as well as skills-based programmes, such as parent skills and advocacy (e.g. Incredible Years programme) and 'Eastern Arts' (e.g. yoga, meditation and mindfulness). For the nuanced detail on effectiveness, refer to Chapter 6. Importantly, the young person themselves did not necessarily need to be the target of the intervention to reap benefits. For example, treatment of parental mental health problems or substance misuse, or providing carer support for those involved with child protective services could have significant benefit for young people's mental health outcomes. In addition, an interesting finding was the considerable number of generally high quality systematic reviews on parental mental health problems (n=18) and on involvement with child protective services (CPS) or living in care (n=28), with median quality ratings of 8.75 and 6.5 out of 14 respectively.

Broadly, more inconclusive or mixed results were found for the following ACEs (also organised in descending order by number of reviews):

- homelessness;
- parental imprisonment or probation;
- parental separation or divorce.

On the whole, systematic reviews were of good quality, with only a few exceptions of low scoring reviews during quality appraisal. A range of study designs were used, including both traditionally well-regarded methods like randomised controlled trials, and also mixed method approaches to provide a deeper understanding of what works. It was noteworthy that evaluation occurred even in challenging settings, for example, using an outreach approach or working with transient populations, such as with displaced or homeless young people, those in out-of-home care, or with imprisoned parents.

There were significant gaps in the literature on what is effective following experiences of either 'parental imprisonment or probation' or 'parental separation or divorce', with just two systematic reviews on each, and median quality ratings of 5.75 and 2.75 out of 14 respectively. Therefore, much less is known about what might support the mental health of young people after experiencing these ACEs and this represents a gap for future research to address. Notably, there were also fewer than five systematic reviews on 'displacement or being a refugee' and 'bereavement i.e. loss of a parent or close relative', both of which ACEs offer a possible early intervention point for potentially at-risk young people, given both ACEs are often evident to services.

Overall, what came through from this umbrella review was that, for the most part, if young people are identified as struggling with their mental health following exposure to different ACEs, there are options for supporting them, and these need not be late treatment, but rather can take a secondary prevention approach. Though there remains a long way to go to make these interventions available to those who need them, it was hopeful to see that effective and promising interventions exist. More work is needed to understand their cost-effectiveness, as very few studies included this information, though a scarce few alluded to why interventions could be cost-effective. Further work is also urgently needed to understand any risks, harms or unintended consequences arising from intervention, especially if a future care pathway is to involve early identification and intervention. For this, it is imperative to understand who does not benefit from intervention, or under what circumstances, and who may be worse off following intervention, to ensure that there are not iatrogenic effects associated with this approach. In the umbrella review, a few papers commented on risks, harms or

unintended consequences, including ineffectiveness of the intervention, the risk of retraumatisation, and exposure to negative peer influences when institutionalised, to name but a few. Ongoing work on these topics will help provide insights into what works for whom and in what scenarios.

7.2.3.2 What factors are important in order to implement these interventions successfully?

A salient finding with regard to implementation of early interventions was the paucity of information on how eligible young people were identified to be offered intervention. If young people are to be offered effective support, there needs to be a plausible way to identify cohorts of people in the first instance. This gap may in part be attributable to the method chosen for this study, as an umbrella review provides insights in a high-level way from systematic reviews. As such, the primary papers may shed more light on identification methods.

Multi-agency collaboration was highlighted as an important factor for successful implementation, including the need for seamless working between child and adult services. Cohesion of services is likely to be important for implementation; fragmented service provision was frequently cited by young people as a barrier to engagement, as was fear of or lack of trust in professionals. Establishing and maintaining trusting relationships with high quality professionals is likely to underpin the success of any interventions. Intervention settings mattered too, for example, familiar settings may reduce access barriers and stigma around participation. Barriers to effective intervention implementation included regular organisational restructuring, staffing shortages and staff turnover, and limited funding. Moreover, funding issues were highlighted as a driver for reactive treatment over proactive prevention strategies.

Having a way to engage effectively with highly transient populations was also important for intervention success. Specifically, high attrition rates, short placements and transience were cited as challenges in certain settings, such as out-of-home care and in prison populations. In some instances, stand-alone sessions were discussed as a means of increasing engagement and retention. However, this may have unintended consequences, such as encouraging people (parents or children) to opt out of sessions which could undermine effectiveness. Therefore, this would need further evaluation.

Furthermore, comprehensive intervention descriptions were noted to be important (with the suggestion of using the TiDieR method to aid this), as were treatment manuals to aid treatment fidelity. Fidelity to treatment protocols, investment in high quality training, and systems for ongoing supervision and quality control were highlighted as crucial here. The institutional climate either helped

or hindered the implementation of evidence-based practice. There needs to be organisational buy-in, collaborative implementation teams, and opinion leaders to introduce the intervention to the team. Careful planning and gradually phased in interventions might be more successful at gaining staff acceptance and buy-in. Finally, any successful implementation needs to be complemented by a continuing cycle of evaluation and monitoring, with routines created to facilitate this process.

Finally, a key aspect of implementation is having an appropriate system to implement into. The THRIVE model, as used in CAMHS, may offer such a system in which to implement these early interventions (Wolpert et al., 2016). The THRIVE model is a person-centred, needs-based approach to delivering mental healthcare, as opposed to a diagnostic approach. Moreover, THRIVE has physical health and community-based components and, as an integrated service, it may be ideally positioned to enable early identification and intervention to support young people.

7.2.4 Overarching research questions:

7.2.4.1 *To what extent is it possible to measure different ACEs using routinely-collected data? What can be done to mitigate any negative mental health impacts for young people who experience different ACEs?*

Taken together, the findings from each of the research questions help to answer the overarching questions posed in this thesis. In conclusion, it is possible to use routinely-collected data to identify many young people who have experienced at least one ACE, and to measure a variety of different types of childhood adversity. This endeavour is greatly aided by linking data from multiple agencies, rather than using single-agency data alone.

Once young people are identified, if it is warranted, a number of effective and promising early interventions exist to help mitigate poor mental health outcomes following ACE exposure. However, this needs to be balanced against the risk of any harms caused by early intervention, an area in need of greater exploration. Finally, a number of important gaps remain with respect to certain ACEs. Routinely-collected linked data alone was insufficient for detecting many instances of ACEs, and at present, this approach would need combining with other identification methods to avoid young people falling through the gaps. Furthermore, very little research existed on the effectiveness of interventions for some types of ACE.

Table 44 provides a high-level summary of whether the ACEs explored in this thesis were measurable and intervenable. Though there were differing extents to which ACEs were measurable and

intervenable, as alluded to throughout this thesis, for the sake of clarity this information is simply provided in a binary manner (yes/no), with additional notes for context. This gives an indication of gaps in the evidence base for future exploration.

Table 44: Summary of the measurability and intervenability of different ACEs, according to the findings of this thesis

		Measurable in routine data? (Yes/No)	Intervenable in early way? (Yes/No)
ACE type	Physical abuse	Yes	Yes
	Sexual abuse	Yes	Yes
	Psychological/emotional or verbal abuse	Yes	Yes
	Financial abuse	Yes↓ (to small extent)	No* (did not explicitly explore)
	Witnessing or experiencing interpersonal violence (IPV)/domestic violence (DV)	Yes	Yes
	Unspecified or mixed maltreatment	Yes	Yes
	Neglect	Yes	Yes
	Parent or guardian in prison or on probation	No	Yes↓ (to small extent)
	Parent or guardian mental health problems	Yes	Yes
	Parent or guardian substance misuse	Yes	Yes
	Parental separation or divorce	No	Yes↓ (to small extent)
	Death of a parent or guardian	No	Yes↓ (to small extent)
	Involvement with child protective services (CPS) or living in care	Yes	Yes
	Homelessness or unstable housing	Yes	Yes
	Experiencing bullying	No	No* (did not explicitly explore)
	Experiencing racism	No	No* (did not explicitly explore)
	Experiencing violence in the community	No	No* (did not explicitly explore)
	Being a young carer	No	No** (did not explore)

♦ This indicates instances where very little information was available on this ACE, either in routine data or the umbrella review of interventions. For example, fewer than 5 cases of financial abuse were measurable within SAIL (in the cohort with social care involvement only), and it is likely this ACE is significantly under-measured so caution should be taken when interpreting this result in particular.

* The protocol and search strategy for the umbrella review was finalised before these ACEs were added to my definition; therefore, the review was not optimised to identify interventions for these ACEs and probably missed relevant literature. For those marked with a '*', the search strategy could have identified some relevant papers through related ACEs such as physical or emotional abuse, and search terms like 'abuse'. However, for 'being a young carer' (indicated with a **) the search strategy would not identify relevant papers. Therefore, it was not possible to conclude from the umbrella review what interventions are available for these ACEs.

7.2.5 Cross-cutting theme:

7.2.5.1 How can these questions be addressed in ways which minimise health inequalities?

During this thesis, I sought to consider how health inequalities could be minimised. This was highlighted as important by material such as that by Knight and colleagues (2021), Perez (2019) and

Ford and colleagues (2021), which discussed who and what is missing from data, the importance of considering bias at all stages of the data pipeline, and how to shape policy with this in mind.

The best example of addressing health inequalities in this thesis was the Delphi project in which we explicitly expressed this as an aim, carried out purposive sampling to improve the representativeness of our panel of experts, and asked about the extent to which we had considered under-served populations. This ultimately resulted in the inclusion of relevant risk factors for certain groups, and the addition of a specific domain in the final risk factor framework to bring salient risk factors to the fore. As this framework will be used to inform data curation, extraction, and prioritisation processes within the Timely team's work, the explicit consideration of health inequalities from the outset should help to ensure CADRE is a more representative database, and that subsequent early identification models and tools are fairer and less biased.

The work within the SAIL Databank was challenging from the perspective of mitigating health inequalities, and less success was achieved here. By default, the databank has minimal demographic information, consisting of only binary sex variables, and a person's week of birth. When this project began, it would have been possible to apply to access the ONS's 2011 census and link this with other databases, thus providing data on ethnicity for some individuals, though it is unclear how many people this would relate to. However, the access process to use any ONS data was much longer and more time-intensive, so a pragmatic decision was made not to pursue it at this point, and first to work with the 18 databases to which we already had access. After the project had ended, SAIL acquired access to the 2021 census, providing more up-to-date information on self-reported ethnicity. Future work could also explore results in terms of deprivation, using a derived variable of the Welsh Index of Multiple Deprivation (WIMD), which was created by the ADP during the linkage of our data.

When working in the SAIL Databank, it was possible to explore experiences of some young people from under-served groups. For example, the project utilised three social care databases and measured ACEs in this population. It also utilised a substance misuse database to understand ACEs in those young people who have their own experiences of substance misuse. In addition, I attempted to measure homelessness and unstable housing, but the code lists I had access to were not optimised for this and measurement was reliant on databases with smaller coverage, namely the substance misuse database (SMDS) and three social care databases (CINW, CRCS, and LACW).

The study in the SAIL Databank also made use of the GP database, which had a large and representative sample, thus helping to ensure the research was more representative of different populations and mitigating against health inequalities (D. V. Ford et al., 2009; K. H. Jones et al., 2019). However, some young people will have been missed from the cohort by virtue of how the SAIL team carry out data linkage. Specifically, the demographic database (WDSD), from which all cohorts are created, is made up of individuals who have registered with a GP and anyone who has never done so will not feature in the cohort, which invites some potential for bias based on who accesses healthcare.

Finally, in the umbrella review of interventions, it was possible to explore the needs of certain vulnerable groups, such as those with child protective service involvement, or interventions that might help children of parents with mental health problems. Inherently, this review tried to understand which interventions work for whom, and who may not reap the benefits of these interventions, thus considering health inequalities. The review also explicitly sought information on the sex and ethnicity of participants, though it was unusual for this to be reported in the included systematic reviews, probably because of the inherent overview nature of a systematic review. The team also extracted data on other cohort characteristics where these were reported, which on rare occasions led to insights into groups such as individuals identifying as LGBTQ+ or those with conditions such as autism or special educational needs.

In summary, this thesis had some success in exploring how to mitigate health inequalities by making this an explicit aim and cross-cutting theme throughout all research questions. However, there are certainly areas for future work and improvement, especially with respect to better incorporation of ethnicity and deprivation markers in the e-cohort within the SAIL Databank.

7.3 Strengths and limitations of the thesis

The strengths and limitations of each of the three studies are described in the respective chapters of this thesis. In this section, the overall strengths and limitations of the thesis are presented.

7.3.1 Definition of ACEs

An initial strength of this thesis was the definition of adverse childhood experiences which underpinned all of the work. The chosen definition had a large scope, covering many different types of adversity, but also provided clear guardrails around what was out of scope. The definition of ACEs was informed by literature, both traditional and widely-accepted, such as that by Felitti and colleagues (1998), but also more contemporary literature, reflecting the evolving recognition of what constitutes

adversity, such as experiences of bullying, racism, community violence, homelessness, being a young carer and so on (M. Allen & Donkin, 2015; Arseneault, 2018; Lester et al., 2019; Scottish Government, 2017; The Philadelphia ACE Project, 2019; Van Niel et al., 2014). In addition to being informed by published literature, the definition was also iteratively improved upon to include an adversity as defined by social care in Wales, namely ‘financial abuse’, which was identified through analysis using the SAIL Databank (Welsh Government, 2024). This latter addition made the definition more appropriate for routine services, to which this thesis was closely tied.

By choosing a definition which clearly defined what was in and out of scope, some important aspects may not have featured which arguably could have. For this thesis, the most prominent omission was probably that of ‘poverty’, ‘financial hardship’ or ‘deprivation’. There is clear evidence to suggest the link between poverty in childhood and poor mental health outcomes (Deighton et al., 2019; Lim, 2019; Samaan, 2000), and this is arguably an area garnering more attention over time. There is literature to show how poverty or low socioeconomic status can both mediate and moderate the relationship between ACEs and poor health (Shah & Marie-Mitchell, 2019), as well as a young person’s likelihood of experiencing certain ACEs (Foster, Brooks-Gunn, & Martin, 2007). Moreover, this has been demonstrated using the SAIL Databank, in a study which found an increased likelihood of becoming a looked-after child for those in the most deprived areas, using a data linkage methodology and survival analysis of an electronic cohort of 395,610 young people born between 2006 and 2021 (Melis et al., 2023). Though the present project did not have access to variables on poverty specifically, indicators of area-level deprivation would have been available, and it would also have been possible to link other databases, such as the Millennium Cohort Study (MCS)⁹, which includes variables relating to income and poverty.

There are some arguments for treating poverty as a separate but important factor from adverse childhood experiences. Firstly, most of the experiences included in this thesis’s definition of ACEs could occur as a single-event and still be impactful on mental health outcomes, as well as occurring repeatedly or in a sustained manner. In contrast, poverty, by definition, is often a prolonged or chronic experience (i.e. of insufficient funds or material goods), and harm typically occurs from the chronicity of poverty (Lai et al., 2019; The Health Foundation, 2024). Poverty is also conceptually different as it is a broader structural issue (Lacey & Minnis, 2020). Secondly, it may be helpful to separate out poverty from other ACEs to not obscure the relationship between it and the likelihood of experiencing other ACEs, as noted earlier. Finally, it is important to maintain the usefulness of the grouping of ACEs;

⁹ <https://web.www.healthdatagateway.org/dataset/a380bd6b-009f-4b78-b638-ba9ee62be2eb>

the definition may become tautological if anything that is associated with poor outcomes is defined as an ACE, making it impossible to conduct meaningful work on the impact of ACEs. There is an ongoing debate among academics about whether poverty should be included as an ACE, and a consensus has not yet been reached (M. Hughes & Tucker, 2018; Treanor, 2018). Experiences of poverty are clearly important, but within this thesis they were captured within the Delphi framework of all risk factors for mental health problems, rather than in my definition of ACEs.

Another possible limitation of the definition of ACEs used here was its focus on experiences of relevance to Western contexts, in spite of this thesis's aim of considering health inequalities at all stages. This was largely a decision based on brevity, the published evidence base, as well as the source of data the thesis would draw upon (i.e. administrative data from the UK), and the location in which early identification tools are being developed. However, some experiences may be rare in the UK but still be experienced by young people who move to the UK, for example by refugees (Wood et al., 2020). Some questionnaires on adversity and trauma have sought to be more culturally sensitive and include other experiences which may be more common in other countries, such as seeing someone injured or killed, war and conflict, and famine (Bernard et al., 2021; Rutter, 2021; World Health Organization, 2014). Instead, experiences such as these were included within the Delphi framework of risk factors for mental health problems.

7.3.2 Who was present and who was absent

Concerted efforts were made to ensure representativeness at all stages of this PhD, with areas of success, as well as some gaps. In the Delphi survey, having a representative sample was made an explicit aim and purposive sampling was carried out to improve representation of people from minority ethnic backgrounds, though little improvement was achieved. In addition, during this survey, deliberate efforts were made to emphasise risk factors most salient to under-served populations, leading to a domain which highlighted these populations and will help to ensure subsequent data pipelines in the Timely project are more inclusive.

With regard to measuring ACEs in routinely-collected data, I conducted a wide search of different available databases during a scoping phase, identifying 16 potential databases or data havens. Research databases such as the Avon Longitudinal Study of Parents and Children (ALSPAC) and UK Biobank were ruled out due to known biases in who tends to be present and absent from research data (A. Fraser et al., 2013; Schoeler et al., 2023), and this project instead favoured routinely-collected data. The Secure Anonymised Information Linkage (SAIL) Databank was selected as it had near-whole-

population coverage, making it more representative (D. V. Ford et al., 2009; K. H. Jones et al., 2019), and it most closely matched what CADRE aims to be (i.e. bringing together administrative data from healthcare, education, and social care).

The database construction and data linkage process used to create the SAIL Databank affects its representativeness. In its simplest terms, GP registration is used as a proxy for the population of Wales when working with SAIL data. The reliance on GP registration to determine inclusion in the SAIL Databank is a possible source of bias, and could affect who is absent from the data, and subsequent analysis. Firstly, not all General Practice surgeries have data sharing agreements set up with SAIL, although the vast majority do (K. H. Jones, Ford, & Lyons, 2017). As mentioned previously, another issue with using GP registration as a proxy for the whole population is that some individuals will not be registered with a GP, and this might be more common in some groups who are considered underserved populations (Corcadden et al., 2018; Healthwatch, 2017). In addition, the data linkage process could have particular significance when trying to measure childhood adversities. It is conceivable that experience of certain ACEs may increase the likelihood of a young person's record not being successfully linked. For example, children who are adopted are given a new NHS number (NHS England, 2023), meaning their pre- and post-adoption data are harder to link. In addition, young people who have experienced domestic violence may move addresses many times with their non-violent parent (e.g. moving into women's shelters) in order to avoid violence at home, or young people could use pseudonyms (or legally change their name), both of which might increase the chance that probabilistic linkage fails (Pearce, Borschmann, Young, & Kinner, 2023; Tibble et al., 2018). Furthermore, those with no fixed abode may not register with a GP (Healthwatch, 2017). These issues are in addition to the issues about presence in specific databases; this would lead to young people not featuring in the baseline database in the first instance to even know they were absent from other databases (such as healthcare and education databases). Though GP registration is not a perfect proxy of the Welsh population, and there is scope for substantial bias for the reasons outlined above, this method facilitates the data linkage of records from a huge cohort of people, enabling research which would not otherwise be possible.

Finally, in the umbrella review, minimisation of bias and inequalities were considered at various stages, with careful consideration for how to be inclusive of young people. Firstly, unlike many systematic reviews and at the advice of a medical librarian, no language limits were set for the search strategy, and included papers were not limited by country, thus drawing from a more diverse range of literature. The variables extracted during data collection included (where available) sex, age range,

ethnicity, pre-existing diagnoses, and any intervention modifications to meet the needs of certain groups. Other data were extracted too which were not presented in this thesis but may be used in subsequent work, including data on 'the voice of the young person' (i.e. quotes and comments on acceptability aspects of interventions, though these were rare due to the high-level nature of systematic reviews). In addition, the research team comprised a mix of professional expertise, including psychology, public health, medicine, and social work, helping discussion remain grounded in health and care practice. Finally, by not excluding literature based on quality assessment ratings as the Lester team had (Lester et al., 2019), the likelihood of including more diverse research methods and populations may have been improved, helping to ensure this review had greater coverage of ACEs experienced by different groups of young people.

7.3.3 Re-use of existing data for research purposes

Various organisations and individuals agree that routine data should be re-used for the purposes of research, which could in the longer term help patient outcomes and improve population health and wellbeing. In fact, many organisations are set up with the purpose of enabling this endeavour, including the HDR UK, ADR UK and DATAMIND, among many others (ADR UK, 2024a; DATAMIND, 2023; Health Data Research UK (HDR UK), 2024). Moreover, and very importantly, members of the public tend to be in favour of the sharing and secondary analysis of their data, within certain boundaries. For example, in a large UK-based survey of just under 30,000 people, there was net support for healthcare data sharing without explicit consent with the NHS, academic institutions, and national charities, though more ambivalence and opposition when it came to data sharing with profit-making companies, including those researching treatments (L. A. Jones et al., 2022).

The value of secondary analysis of existing data is highlighted in a report by the UK Clinical Research Collaboration (UKCRC), who are a collection of organisations whose work focuses on establishing the UK as a world leader in clinical research (UKCRC, 2008). This includes a commitment to use electronic data within reasonable boundaries, i.e. in keeping with principles of data protection and confidentiality (UKCRC, 2007). The UKCRC report sought to provide information on various possible research applications to the Department of Health Directorate of Research and Development and NHS Connecting for Health (NHS CfH) (UKCRC, 2007). The report, which included various simulations, noted the benefits that can be realised for different aspects of patient care, as well as for research (including clinical, public health and health service research). It noted the incredible capacity the UK has for data linkage, health monitoring and intervention. It also acknowledged the potential to address public health concerns, stating:

“Large-scale epidemiological studies have a distinguished tradition of contributing to the prevention and control of disease in populations... Linkage of routine health service data, environmental, fiscal and educational data, and data on vital events such as births and deaths can enhance our understanding, and strengthen the scientific basis of strategies to maintain the health and wellbeing of the population and the [sic] prevent and control disease.” (UKCRC, 2007)

Moreover, the report noted the UK’s unique position in particular to conduct such work, stating:

“The NHS throughout the UK treats the single largest group of people anywhere in the world, and keeps detailed records on all of them from birth to death... This access to and linkage of data will help researchers to understand the causes of diseases better, and to find new ways to prevent and treat many different conditions.” (UKCRC, 2007)

Though the opportunities afforded by secondary analysis of routinely-collected data are clear, it certainly comes with significant challenges, many of which were encountered in the course of this thesis. Firstly, despite working on a cost-recovery model (i.e. not profit-making), it was very expensive to access the SAIL Databank and link the data (over £16,500 excluding VAT) and additional funding was required to facilitate this part of my thesis. This fee goes towards costs such as ensuring the security, infrastructure and governance structures of the databank, as well as funding analysts’ time to support projects. Once data access was granted, the limited metadata for the 18 databases was very difficult to work with, and data dictionaries were held quite disparately, with different members of staff recommending different sources. Variable descriptions sometimes had errors and none of the variables in the published data dictionaries had field-level data, for example, the variable ‘GNDR’ would have a description like ‘This variable is the sex of the child recorded at birth.’ However, there would be no information to say that the possible options were ‘1’, ‘2’, and ‘17’, nor that ‘17’ related to missing data, and ‘1’ and ‘2’ were male and female, respectively. This made the task of mapping the 287 risk factors from the Delphi framework to the SAIL data dictionaries for the 18 databases extremely time-consuming and laborious, involving continual back-and-forth with the SAIL team to check the meaning of variables and how to interpret results. The SAIL team are continually improving the metadata over time, but they are also constantly expanding the number of databases they house, meaning the metadata lags behind the databank’s expansion. Moreover, it was challenging working with a resource that had great deals of legacy information replaced by newer information with little clear signposting. A further challenge was the lack of induction or clear instructions for setting up the project within the SAIL gateway. However, since my project concluded, the SAIL team have introduced

a self-guided induction training pack¹⁰ based on feedback from users, including my own, and this should improve the process of new users getting started in the gateway. Finally, work in the databank was significantly slowed due to the fact that the system would frequently crash, inefficient code might not run on larger databases, such as the GP data (without it being clear that this was the reason for glitches), and SAIL would have regularly scheduled and unscheduled downtime to ensure the security and workings of the system. There were steps being taken to improve the computational power and system architecture underlying the platform so these issues should ease over time. However, with any big data such as this, the challenges around time, cost, and resource should be considered alongside the very obvious benefits described throughout this thesis. These experiences also helped to shape the design of CADRE, which seeks to address several of the challenges experienced.

7.3.4 Scope, scale, novelty, cohesion, and contribution to the wider field

A further strength was the scope and scale of the studies within this thesis, as well as the novelty of the work and the way each study built on the previous as a plausible foundation for a care pathway. With respect to scope and scale, the Delphi study resulted in a framework of nearly 300 risk factors for predicting mental health problems, which I then mapped to the data dictionaries of 18 routine databases from the SAIL Databank. We then accessed and linked these 18 databases. To our knowledge, these databases had never previously been linked together, and this resulted in a huge baseline cohort of over 1.1 million young people. My thesis specifically brought together 12 of these data sources and measured a wide range of adversities in this cohort. Furthermore, the inclusion of social care data alongside that from health was an important addition which is sometimes omitted, in favour of linking health and education data alone (Downs et al., 2017; Soneson et al., 2023). Through its inclusion, it was possible to measure additional instances of ACEs such as homelessness, parental mental health problems, parental substance misuse, and involvement with child protective services (CPS) or living in care. The umbrella review synthesised a huge amount of rich literature, first through the chosen methodology of an umbrella review specifically, which brought together systematic reviews that already contained many primary sources, but also through the final inclusion of 82 systematic reviews and meta-analyses from a range of countries and languages. This resulted in more data than it was possible to condense into this thesis alone, so the key information was presented here. The review also focused on a wider age range of young people than are often included, recognising the importance of young adulthood in mental health (Blakemore, 2019; Kessler et al., 2005). With regard to cohesion, each study in this thesis could be used to inform a future care pathway to support young people which makes better use of routine data to identify individuals who may

¹⁰ <https://dataciseopenlearning.org/sail-databank/>

benefit from additional support. The impact of early intervention would need to be rigorously tested to ensure that there are not unintended consequences or harms. However, it is possible to envisage a future (albeit relatively far-off) where professionals could identify young people exposed to childhood adversities, offer a needs-based early intervention identified in the umbrella review, and measure the impact of intervention on mental health outcomes using routine data relating to the young person.

This thesis also made three other important contributions to the field. Firstly, as was set out as a primary aim, it helped to understand the extent to which routine data could be used for the purposes of measuring ACEs. This was important for a number of reasons. For example, it can be more efficient to re-use data rather than collect new data for each research project (UK Clinical Research Collaboration (UKCRC), 2007). In addition, routine data might also be more inclusive of different groups of individuals than research data, though it is not without its own limitations (Inclusive Data Taskforce, 2021; Routen et al., 2022). Furthermore, for ACEs specifically, it is important that young people are not repeatedly asked to retell distressing experiences without good cause or outcome, as this can increase distress and, in some instances, result in retraumatisation (Substance Abuse and Mental Health Services Administration (SAMHSA), 2014). Secondly, this thesis did not seek to just measure or screen for ACEs, but also to suggest what meaningful interventions could be delivered where indicated, so that this screening makes a difference to the lives of young people. Thirdly, this work was what was called for by practitioners, and included as a recommendation from a serious case review, suggesting it is relevant and wanted by those who seek to promote young people's safety and wellbeing.

One of the key recommendations from the serious case inquiry following the death of the young girl, Victoria Climbé (Laming, 2003), was to test the feasibility of building a national children's database. The review said:

"Those who deliberately harm children have a tendency to cover their tracks. Poor record-keeping, doubts about the exchange of information between services, and inadequate client information systems make that easy..."

In the circumstances set out above, there is much to be said in favour of a database covering all children. I was told that such a database is technically feasible and that there are many much larger systems. The benefit of such a database would be that every new contact with a child by a member of staff from any of the key services would initiate an entry that would build

up a picture of the child's health, developmental and educational needs. I have recommended that the Government commission work to look into the feasibility of such a national database, and this may result in pilot studies being carried out.” (Laming, 2003)

This thesis illustrates the feasibility of bringing together such a database, including information on health and development. Furthermore, though it was not used for the purpose of measuring ACEs, educational information was able to be linked to this database too, as recommended by the serious case review.

Finally, this work has laid the foundations for a Master's student, Charlotte Burdge, to continue further exploration within the SAIL Databank, with her project seeking to understand whether the measurement of different ACEs can actually help to predict the occurrence of common mental disorders (CMD), i.e. anxiety and depression, in young people.

7.4 Future work

The work in this thesis has provided a number of interesting and useful avenues for further exploration. A few of these are listed below:

- Continue development of the CADRE database.
- Develop early identification model prototypes using the risk factors highlighted in the Delphi framework, building on the initial work in our technical report (Parkin et al., 2023). Test the predictive utility of these models and explore their biases.
- Explore whether ACEs specifically are predictive of developing mental health problems, and if so, explore which ACEs or which combination of ACEs are particularly predictive. This could point towards areas for targeted and proportionate support.
- Explore mitigations to improve the fairness and reduce inbuilt bias of models for those who are missing from routine data sources, or who have reduced access to such services.
- Continue with the ongoing patient and public involvement on the acceptable use of routine data to develop early identification tools for mental health. Amongst others, questions could include:
 - ethical questions about the possible rights of individuals to have certain information ‘forgotten’ by the system (e.g. adversities erased from their record upon request) versus the risk that this might mean they do not receive such holistic care which considers their personal circumstances, as well as the risk of creating further bias in routine data which might exacerbate inequities in the care of others;

- whether and how young people and guardians would want to be informed about the outcomes of the early identification model;
- whether there are any downsides to earlier identification (e.g. a labelling effect) and how these can be mitigated;
- how models should be translated into tools in practice;
- what settings would benefit from such tools;
- how professionals would interact with these tools;
- who should and should not have sight of these tools and their outputs;
- how a future care pathway might look if it is to serve the population;
- how models can be improved over time.
- For ACEs which were poorly measured in the present thesis (either unable to be measured or measured with low confidence), explore alternative measurement methods, including combining multiple methods. For example:
 - linkage of parent, sibling and/or household data (using SAIL's residential identifiers for the latter);
 - linkage of additional routine data sources, such as data from the Department for Justice, and Department for Work and Pensions;
 - linkage of routine data to other data sources, such as cohort studies and research data, for example the Avon Longitudinal Study of Parents and Children (ALSPAC) and the Millennium Cohort Study (MCS);
 - natural language processing (NLP) methods to interrogate free-text notes in other data sources. (Of note, the SAIL Databank does not contain unstructured data so NLP would not be an option with these data).
- Conduct further research to fill the evidence gaps for ACEs where little information was available on early intervention options. For example, for young people experiencing parental imprisonment, or the death of a parent or close relative.
- Building on the umbrella review of interventions, carry out a deeper investigation into the potential harms or unintended consequences of intervening earlier to help the mental health of young people who have experienced ACEs, with a particular focus on reducing health inequalities. This investigation could take the form of a scoping review of this alone, interviews or focus groups with young people and professionals, conversations with the professionals involved in the primary studies included in the umbrella review of interventions, small-scale trials with this question in mind, or a mixed methods approach which incorporates combinations of these methods.

- Engage with relevant stakeholders (including health services, community centres, schools, child protection services, youth clubs, charitable organisations etc) to understand how early interventions might best fit into existing care pathways, as well as how to imagine new care pathways that move towards prevention of mental health problems, whilst leaving sufficient resources for treatment for those who need it.
- If accurate predictive models can be developed, carry out a trial to understand whether earlier interventions can help young people's mental health trajectories.
- Explore dosage effects of early interventions (i.e. what is proportionate and meaningful), and what is the cost-benefit of intervention.

7.5 Conclusions

We are not in a place where population-wide screening for ACEs is appropriate, nor does this thesis advocate for this. Importantly, ACEs do not yet meet the National Screening Committee's criteria for this (UK National Screening Committee, 2015). There is good evidence for the link between ACEs and a range of adverse outcomes, and there are a variety of potentially effective interventions. However, there is limited evidence on the potential for screening or routine enquiry to reduce morbidity and mortality, and limited evidence on possible harms from screening, as well as a lack of consistent evidence on screening tools and administration settings (Gentry & Paterson, 2021). It would seem unethical or irresponsible to routinely screen for ACEs, which can be a highly personal and sensitive topic, if screening does not lead to meaningful action where it is indicated. Critically too, ACE exposure alone is not guaranteed to lead to poor mental health problems, and a number of other factors are important, including the number of experiences, severity, duration, subjective experience and surrounding context. This field would also benefit from rich and representative qualitative studies with people who have experienced ACEs to better understand their perspectives on the use of routinely collected linked data for the measurement and early intervention of ACEs.

That said, though routine screening for ACEs at a population level is not warranted at present, we can be ACE-informed in our service provision and make better use of existing data on this sensitive topic. In this thesis, I sought to understand whether taking an ACE-informed approach, specifically by understanding the prevalence, impact, and potential mitigators of ACEs, could help to target mental health resources. It is widely accepted that most of the determinants of health do not sit with healthcare (Dahlgren & Whitehead, 1991, 2021; Sederer, 2016), and this shone through in this thesis. 'Targeting mental health resources' might only minorly involve mental health services themselves; instead this thesis highlights the many crucial actors needed to identify ACEs and support young

people's mental health and wellbeing following exposure. As referenced in the title of this thesis, many different organisations hold pieces of the same puzzle; linkage and use of routinely-collected multi-agency data helps to view more of the puzzle. Secondary prevention, namely prevention and early intervention for mental health problems after ACE exposure, forms an invaluable part of the puzzle of addressing ACEs.

Through the course of this PhD, I co-developed a framework of risk factors for mental health problems to understand what variables should be extracted and included if early identification tools for young people's mental health problems are to be accurate. I then created a linked database of routinely-collected data from over 1.1 million young people in Wales, UK, bringing together 12 databases within the SAIL Databank for the first time to understand the recorded prevalence and measurability of different childhood adversities. I concluded with an umbrella review which synthesised a vast amount of information from 82 systematic reviews and meta-analyses to understand what prevention and early intervention strategies might mitigate poor mental health outcomes after exposure to different ACEs. Taken together, these three studies help to form the early foundations of possible care pathways to support young people's mental health and wellbeing, which consist of early identification and early intervention in an ACE-informed and data-driven way. Ongoing work is needed to ensure that these care pathways are developed in a way that is acceptable to young people, their caregivers, and professionals, and the Timely team has a programme of work focused on this. Future work is also needed to ensure that support is feasible, implementable, affordable, proportionate, effective and continually evaluated, and that health inequalities and biases are continually considered, ensuring harms and unintended consequences are addressed. Finally, there remain gaps in measuring and intervening following exposure to certain ACEs and this should be a priority going forward.

This thesis contributes a small but significant part of the puzzle of ACEs and mental health outcomes, with the intention of building the evidence base about what helps young people to thrive after experiencing ACEs, and helping to shift the narrative towards viewing ACEs as a tractable issue. Poor outcomes are by no means guaranteed following exposure to adverse experiences in childhood. Addressing ACEs could benefit young people, their families, future adults, and wider society as a whole.

8 Bibliography

- Aafjes-van Doorn, K., Kamsteeg, C., & Silberschatz, G. (2020). Cognitive mediators of the relationship between adverse childhood experiences and adult psychopathology: A systematic review. *Development and Psychopathology*, 32(3), 1017–1029.
<https://doi.org/http://dx.doi.org/10.1017/S0954579419001317>
- ADR UK. (2021). Our Mission. Retrieved May 14, 2024, from <https://www.adruk.org/our-mission/our-mission/>
- ADR UK. (2024a). About ADR UK. Retrieved July 9, 2024, from <https://www.adruk.org/about-us/about-adr-uk/>
- ADR UK. (2024b). Bias in administrative data and in linked data. Retrieved August 11, 2024, from <https://www.adruk.org/learning-hub/skills-and-resources-to-use-administrative-data/bias-in-administrative-data-and-in-linked-data/>
- Agrawal, J., Lei, Y., Shah, V., Bui, A. L., Halfon, N., & Schickedanz, A. (2024). Young Adult Mental Health Problem Incidence Varies by Specific Combinations of Adverse Childhood Experiences. *Adversity and Resilience Science*. <https://doi.org/10.1007/s42844-024-00140-5>
- Ahern, N. R., Mechling, B., Palumbo, R., & Woodard, E. (2020). Children of Parents With Opioid Use Disorder. *Journal of Psychosocial Nursing and Mental Health Services*, 59(3), 28–34.
<https://doi.org/10.3928/02793695-20201203-03>
- Ainsworth, M. D. S. (1978). The bowlby-ainsworth attachment theory. *Behavioral and Brain Sciences*, 1(3), 436–438.
- All Party Parliamentary Group on a Fit and Healthy Childhood. (2024). *Adverse Childhood Experiences: Roads to Recovery*. Retrieved from <https://www.mqmentalhealth.org/wp-content/uploads/ADVERSE-CHILDHOOD-EXPERIENCES-FINAL-REPORT.pdf>
- Allen, G. (2011). *Early Intervention: The Next Steps - An Independent Report to Her Majesty's Government*. Retrieved from https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/284086/early-intervention-next-steps2.pdf
- Allen, M., & Donkin, A. (2015). The impact of adverse experiences in the home on the health of children and young people, and inequalities in prevalence and effects. *London: UCL Institute of Health Equity*.
- Allnatt, G., Lee, A., Scourfield, J., Elliott, M., Broadhurst, K., & Griffiths, L. (2022). Data resource profile: children looked after administrative records in Wales. *International Journal of Population Data Science*, 7(1), 1752. <https://doi.org/10.23889/ijpds.v7i1.1752>

- Altena, A. M., Brilleslijper-Kater, S. N., & Wolf, J. L. M. (2010). Effective interventions for homeless youth: a systematic review. *American Journal of Preventive Medicine*, 38(6), 637–645.
<https://doi.org/10.1016/j.amepre.2010.02.017>
- Althubaiti, A. (2016). Information bias in health research: Definition, pitfalls, and adjustment methods. *Journal of Multidisciplinary Healthcare*, 9, 211–217.
<https://doi.org/10.2147/JMDH.S104807>
- Andrews, C., Schultze, A., Curtis, H., Hulme, W., Tazare, J., Evans, S., ... Walker, A. (2022). OpenSAFELY: Representativeness of electronic health record platform OpenSAFELY-TPP data compared to the population of England. *Wellcome Open Research*, 7, 1–19.
<https://doi.org/10.12688/wellcomeopenres.18010.1>
- Anthony, R., Paine, A. L., Westlake, M., Lowthian, E., & Shelton, K. H. (2022). Patterns of adversity and post-traumatic stress among children adopted from care. *Child Abuse and Neglect*, 130(P2), 104795. <https://doi.org/10.1016/j.chiabu.2020.104795>
- Arias, D., Saxena, S., & Verguet, S. (2022). Quantifying the global burden of mental disorders and their economic value. *EClinicalMedicine*, 54. <https://doi.org/10.1016/j.eclinm.2022.101675>
- Arkowitz, H., & Lilienfeld, S. O. (2023, March). Is Divorce Bad for Children? *Scientific American*. Retrieved from <https://www.scientificamerican.com/article/is-divorce-bad-for-children/>
- Armfield, J. M., Gnanamanickam, E. S., Johnston, D. W., Preen, D. B., Brown, D. S., Nguyen, H., & Segal, L. (2021). Intergenerational transmission of child maltreatment in South Australia, 1986–2017: a retrospective cohort study. *The Lancet Public Health*, 2667(21), 1–12.
[https://doi.org/10.1016/s2468-2667\(21\)00024-4](https://doi.org/10.1016/s2468-2667(21)00024-4)
- Arseneault, L. (2018). Annual Research Review: The persistent and pervasive impact of being bullied in childhood and adolescence: implications for policy and practice. *Journal of Child Psychology and Psychiatry*. Retrieved from https://ezp.lib.cam.ac.uk/login?url=https://search.proquest.com/docview/2017690378?accountid=9851&bdid=7112&_bd=Gg5fzsVKzINTRmjBB7Xqed61kcw%3D
- Asmussen, K., Fischer, F., Drayton, E., & McBride, T. (2020). *Adverse childhood experiences: What we know, what we don't know, and what should happen next*. Early Intervention Foundation. London. Retrieved from <https://www.eif.org.uk/report/adverse-childhood-experiences-what-we-know-what-we-dont-know-and-what-should-happen-next>
- Asmussen, K., McBride, T., & Waddell, S. (2019). The Potential of Early Intervention for Preventing and Reducing ACE-Related Trauma. *Social Policy and Society*, 18(3), 425–434.
<https://doi.org/10.1017/S1474746419000071>
- Bailey, C., Klas, A., Cox, R., Bergmeier, H., Avery, J., & Skouteris, H. (2018). Systematic review of

- organisation-wide, trauma-informed care models in out-of-home care (OoHC) settings. *Health & Social Care in the Community*, 27(3), e10–e22. <https://doi.org/10.1111/hsc.12621>
- Barlow, J., Bennett, C., Midgley, N., Larkin, S. K., & Wei, Y. (2015). Parent-infant psychotherapy for improving parental and infant mental health. *Cochrane Database of Systematic Reviews*, 1(1), 1–129. <https://doi.org/10.1002/14651858.CD010534.pub2>
- Barrett, D., & Heale, R. (2020). What are Delphi studies? *Evidence-Based Nursing*, 23(3), 68–69.
- Barton, S., & Armstrong, P. (2018). *CBT for Depression: An Integrated Approach* (1st ed.). London: SAGE Publications Ltd.
- Bassuk, E. L., DeCandia, C. J., Tsertsvadze, A., & Richard, M. K. (2014). The effectiveness of housing interventions and housing and service interventions on ending family homelessness: a systematic review. *American Journal of Orthopsychiatry*, 84(5), 457–474. <https://doi.org/10.1037/ort0000020>
- Bateman, A., Fonagy, P., Campbell, C., Luyten, P., & Debbané, M. (2023). Trauma. In *Cambridge Guide to Mentalization-Based Treatment (MBT)* (pp. 277–297). Cambridge: Cambridge University Press. Retrieved from https://www.cambridge.org/core/books/cambridge-guide-to-mentalizationbased-treatment-mbt/trauma/CB8F970F4535A19BF4FACF8D3DA40AE4?utm_campaign=shareaholic&utm_medium=copy_link&utm_source=bookmark
- Baune, B. (2019). *Personalized Psychiatry*. London: Academic Press.
- BBC. (2005). System “failed starving children.” Retrieved May 24, 2024, from http://news.bbc.co.uk/1/hi/england/south_yorkshire/4546736.stm
- Becker, L., & Oxman, A. (2008). Overview of reviews. In J. Higgins & S. Green (Eds.), *Cochrane handbook for systematic reviews of interventions version 5.1.0 [updated March 2011]*. The Cochrane Collaboration.
- Bee, P., Bower, P., Byford, S., Churchill, R., Calam, R., Stallard, P., ... Abel, K. (2014). The clinical effectiveness, cost-effectiveness and acceptability of community-based interventions aimed at improving or maintaining quality of life in children of parents with serious mental illness: a systematic review. *Health Technology Assessment*, 18(8), 1–250. <https://doi.org/https://dx.doi.org/10.3310/hta18080>
- Bellis, M. A., Ashton, K., Hughes, K., Ford, K., Bishop, J., & Paranjothy, S. (2015). *Adverse Childhood Experiences and their impact on health-harming behaviours in the Welsh adult population*. Public Health Wales NHS Trust. Retrieved from http://researchonline.ljmu.ac.uk/id/eprint/2648/1/ACE_Report_FINAL_%28E%29.pdf
- Bellis, M. A., Hughes, K., Ford, K., Ramos Rodriguez, G., Sethi, D., & Passmore, J. (2019). Life course

- health consequences and associated annual costs of adverse childhood experiences across Europe and North America: a systematic review and meta-analysis. *The Lancet Public Health*, 4(10), e517–e528. [https://doi.org/10.1016/S2468-2667\(19\)30145-8](https://doi.org/10.1016/S2468-2667(19)30145-8)
- Bellis, M. A., Wood, S., Hughes, K., Quigg, Z., Butler, N., Brown, C., & Passmore, J. (2023). *Tackling Adverse Childhood Experiences (ACEs): State of the Art and Options for Action*. Public Health Wales NHS Trust. Cardiff, UK. Retrieved from www.nationalarchives.gov.uk/doc/open-government-licence/version/3/
- Beresford, B., Clarke, S., Gridley, K., Parker, G., Pitman, R., Spiers, G., & Light, K. (2008). *Technical report for SCIE research review on access, acceptability and outcomes of services/interventions to support parents with mental health problems and their families*. Retrieved from <https://www.york.ac.uk/inst/spru/research/pdf/SCIEReview2.pdf>
- Bergman, A.-S., Axberg, U., & Hanson, E. (2017). When a parent dies – a systematic review of the effects of support programs for parentally bereaved children and their caregivers. *BMC Palliative Care*, 16(39), 1–15. <https://doi.org/10.1186/s12904-017-0223-y>
- Bergström, M., Cederblad, M., Håkansson, K., Jonsson, A. K., Munthe, C., Vinnerljung, B., ... Sundell, K. (2020). Interventions in Foster Family Care: A Systematic Review. *Research on Social Work Practice*, 30(1), 3–18. <https://doi.org/10.1177/1049731519832101>
- Bernard, D. L., Calhoun, C. D., Banks, D. E., Halliday, C. A., Hughes-Halbert, C., & Danielson, C. K. (2021). Making the “C-ACE” for a Culturally-Informed Adverse Childhood Experiences Framework to Understand the Pervasive Mental Health Impact of Racism on Black Youth. *Journal of Child and Adolescent Trauma*, 14(2), 233–247. <https://doi.org/10.1007/s40653-020-00319-9>
- Blakemore, S. J. (2019). Adolescence and mental health. *The Lancet*, 393(10185), 2030–2031. [https://doi.org/10.1016/S0140-6736\(19\)31013-X](https://doi.org/10.1016/S0140-6736(19)31013-X)
- Bowlby, J. (1969). *Attachment and loss*. Pimlico, London: Random House.
- British Medical Association. (2024). *“It’s broken” Doctors’ experiences on the frontline of a failing mental healthcare system*. London. Retrieved from <https://www.bma.org.uk/media/ddclsiii/bma-mental-health-report-2024-web-final.pdf>
- Bronfenbrenner, U. (1979). *The ecology of human development: Experiments by nature and design*. Harvard university press.
- Bronfenbrenner, U., & Morris, P. A. (2006). The bioecological model of human development. In R. M. Lerner & W. E. Damon (Eds.), *Handbook of child psychology: Vol 1, theoretical models of human development* (pp. 793–828). West Sussex: Wiley.
- Bröning, S., Kumpfer, K., Kruse, K., Sack, P.-M., Schaunig-Busch, I., Ruths, S., ... Thomasius, R. (2012).

- Selective prevention programs for children from substance-affected families: a comprehensive systematic review. *Substance Abuse Treatment, Prevention, and Policy*, 7(23), 1–17.
<https://doi.org/10.1186/1747-597X-7-23>
- Burgan, A., Bernal-Delgado, E., Kuchinke, W., van Staa, T., Cunningham, J., Lettieri, E., ... Chène, G. (2017). Health Data for Public Health: Towards New Ways of Combining Data Sources to Support Research Efforts in Europe. *Yearbook of Medical Informatics*, 26(1), 235–240.
<https://doi.org/10.15265/IY-2017-034>
- Calhoun, S., Conner, E., Miller, M., & Messina, N. (2015). Improving the outcomes of children affected by parental substance abuse: a review of randomized controlled trials. *Substance Abuse & Rehabilitation*, 6, 15–24. <https://doi.org/10.2147/SAR.S46439>
- Campbell, K. A., Wood, J. N., Lindberg, D. M., & Berger, R. P. (2021). A standardized definition of near-fatal child maltreatment: Results of a multidisciplinary Delphi process. *Child Abuse and Neglect*, 112, 104893. <https://doi.org/http://dx.doi.org/10.1016/j.chiabu.2020.104893>
- Canva UK Operations Ltd. (2018). Flourish [Computer program]. Retrieved from <https://flourish.studio>
- Care Quality Commission. (2018). *Are we listening? Review of Children and Young People's Mental Health Services*. London. Retrieved from https://www.cqc.org.uk/sites/default/files/20180308b_arewelisting_report.pdf
- Center for Disease Control and Prevention. (2019). Preventing Adverse Childhood Experiences (ACEs): Leveraging the Best Available Evidence, 1–40.
- Chamberlain, C., Gee, G., Harfield, S., Brennan, S., Clark, Y., Mensah, F., ... Dyal, D. (2019). Parenting after a history of childhood maltreatment: A scoping review and map of evidence in the perinatal period. *PLoS ONE*, 14(3), e0213460.
<https://doi.org/http://dx.doi.org/10.1371/journal.pone.0213460>
- Chandan, Joht S, Thomas, T., Gokhale, K. M., Bandyopadhyay, S., Taylor, J., & Nirantharakumar, K. (2019). The burden of mental ill health associated with childhood maltreatment in the UK, using The Health Improvement Network database: a population-based retrospective cohort study. *The Lancet Psychiatry*, 6(11), 926–934.
- Chandan, Joht Singh, Gokhale, K. M., Bradbury-Jones, C., Nirantharakumar, K., Bandyopadhyay, S., & Taylor, J. (2020). Exploration of trends in the incidence and prevalence of childhood maltreatment and domestic abuse recording in UK primary care: a retrospective cohort study using 'the health improvement network' database. *BMJ Open*, 10(6), e036949.
- Chandan, Joht Singh, Okoth, K., Gokhale, K. M., Bandyopadhyay, S., Taylor, J., & Nirantharakumar, K. (2020). Increased cardiometabolic and mortality risk following childhood maltreatment in the

- United Kingdom. *Journal of the American Heart Association*, 9(10), e015855.
- Chekroud, A. M., Zotti, R. J., Shehzad, Z., Gueorguieva, R., Johnson, M. K., Trivedi, M. H., ... Corlett, P. R. (2016). Cross-trial prediction of treatment outcome in depression: A machine learning approach. *The Lancet Psychiatry*, 3(3), 243–250. [https://doi.org/10.1016/S2215-0366\(15\)00471-X](https://doi.org/10.1016/S2215-0366(15)00471-X)
- Chen, C. Y.-C., & Panebianco, A. (2018). Interventions for young bereaved children: A systematic review and implications for school mental health providers. *Child & Youth Care Forum*, 47(2), 151–171. <https://doi.org/10.1007/s10566-017-9426-x>
- Chen, J., Chen, X., Leung, S. S. M., & Tsang, H. W. H. (2021). Potential impacts, alleviating factors, and interventions for children of a parent with schizophrenia: A scoping review. *Children and Youth Services Review*, 120. <https://doi.org/10.1016/j.childyouth.2020.105751>
- Cheong, S. K., Lang, C. P., Hemphill, S. A., & Johnston, L. M. (2016). What constitutes self-concept for children with CP? A Delphi consensus survey. *Journal of Developmental and Physical Disabilities*, 28(2), 333–346. <https://doi.org/10.1007/s10882-015-9471-z>
- Children’s Commissioner. (2023). Children’s Mental Health Services 2021-22, (March), 1–53. Retrieved from <https://www.childrenscommissioner.gov.uk/resource/29751/>
- Choi, G. J., & Kang, H. (2023). Introduction to Umbrella Reviews as a Useful Evidence-Based Practice. *Journal of Lipid and Atherosclerosis*, 12(1), 3–11. <https://doi.org/10.12997/jla.2023.12.1.3>
- Compton, M., & Shim, R. (2015). The social determinants of mental health. *Focus*, 13(4), 419–425. <https://doi.org/10.1176/appi.focus.20150017>
- Coren, E., Hossain, R., Pardo Pardo, J., & Bakker, B. (2016). Interventions for promoting reintegration and reducing harmful behaviour and lifestyles in street-connected children and young people. *Cochrane Database of Systematic Reviews*, (1), 1–126. <https://doi.org/10.1002/14651858.CD009823.pub3>
- Corscadden, L., Levesque, J. F., Lewis, V., Strumpf, E., Breton, M., & Russell, G. (2018). Factors associated with multiple barriers to access to primary care: An international analysis. *International Journal for Equity in Health*, 17(1), 1–10. <https://doi.org/10.1186/s12939-018-0740-1>
- Corwin, D. L., Alexander, R., Blair-Merritt, M., Block, R., Davis, M., James, L., ... Schneider, D. (2015). *Adverse Childhood Experiences: Informing Best Practices*. Retrieved from http://www.avahealth.org/aces_best_practices/
- Cox, M. J., & Paley, B. (2003). Understanding Families as Systems. *Current Directions in Psychological Science*, 12(5), 193–196. <https://doi.org/10.1111/1467-8721.01259>
- Crowley, R., Parkin, K., Rocheteau, E., Massou, E., Friedmann, Y., John, A., ... Moore, A. (2025).

- Machine Learning for Prediction of Childhood Mental Health Problems in Social Care. *BJPsych Open*, 11(3), 1–9. <https://doi.org/10.1192/bjo.2025.32>
- Cuijpers, P., Smit, F., Unger, F., Stikkelbroek, Y., Ten Have, M., & De Graaf, R. (2011). The disease burden of childhood adversities in adults: A population-based study. *Child Abuse and Neglect*, 35(11), 937–945. <https://doi.org/10.1016/j.chiabu.2011.06.005>
- Cuijpers, P., Weitz, E., Karyotaki, E., Garber, J., & Andersson, G. (2015). The effects of psychological treatment of maternal depression on children and parental functioning: a meta-analysis. *European Child & Adolescent Psychiatry*, 24(2), 237–245. <https://doi.org/10.1007/s00787-014-0660-6>
- Dahlgren, G., & Whitehead, M. (1991). *Policies and strategies to promote social equity in health*. Stockholm, Sweden: Institute for Futures Studies.
- Dahlgren, G., & Whitehead, M. (2021). The Dahlgren-Whitehead model of health determinants: 30 years on and still chasing rainbows. *Public Health*, 199, 20–24. <https://doi.org/10.1016/j.puhe.2021.08.009>
- Dalkey, N., & Helmer, O. (1963). An experimental application of the Delphi method to the use of experts. *Management Science*, 9(3), 458–467.
- DATAMIND. (2023). Findable, Accessible, Interoperable, & Reusable (FAIR) curated mental health data.
- Davey, C. G., & McGorry, P. D. (2019). Early intervention for depression in young people: a blind spot in mental health care. *The Lancet Psychiatry*, 6(3), 267–272. [https://doi.org/10.1016/S2215-0366\(18\)30292-X](https://doi.org/10.1016/S2215-0366(18)30292-X)
- de López, K. J., Søndergaard Knudsen, H., & Hansen, T. G. B. (2020). What Is Measured in Bereavement Treatment for Children and Adolescents? A Systematic Literature Review. *Illness, Crisis, and Loss*, 28(4), 363–387. <https://doi.org/http://dx.doi.org/10.1177/1054137317741713>
- de Man, Y., Wieland-Jorna, Y., Torensma, B., de Wit, K., Francke, A. L., Oosterveld-Vlug, M. G., & Verheij, R. A. (2023). Opt-In and Opt-Out Consent Procedures for the Reuse of Routinely Recorded Health Data in Scientific Research and Their Consequences for Consent Rate and Consent Bias: Systematic Review. *Journal of Medical Internet Research*, 25, e42131. <https://doi.org/10.2196/42131>
- Deighton, J., Lereya, S. T., Casey, P., Patalay, P., Humphrey, N., & Wolpert, M. (2019). Prevalence of mental health problems in schools: Poverty and other risk factors among 28 000 adolescents in England. *British Journal of Psychiatry*, 215(3), 565–567. <https://doi.org/10.1192/bjp.2019.19>
- Di Lemma, L. C. G., Davies, A. R., Ford, K., Hughes, K., Homolova, L., Gray, B., & Richardson, G. (2019). *Responding to adverse childhood experiences: an evidence review of interventions to prevent*

and address adversity across the life course.

- Digital Scholar. (2023). Zotero: Reference Manager. Virginia, United States: Roy Rosenzweig Center for History and New Media, George Mason University.
- Doidge, J. C., Edwards, B., Higgins, D. J., & Segal, L. (2017). Adverse childhood experiences, non-response and loss to follow-up: Findings from a prospective birth cohort and recommendations for addressing missing data. *Longitudinal and Life Course Studies*, 8(4), 382–400.
<https://doi.org/10.14301/llcs.v8i4.414>
- Dong, M., Anda, R. F., Felitti, V. J., Dube, S. R., Williamson, D. F., Thompson, T. J., ... Giles, W. H. (2004). The interrelatedness of multiple forms of childhood abuse, neglect, and household dysfunction. *Child Abuse & Neglect*, 28(7), 771–784.
- Doughty, B. (2024). MQ joins calls for a public health strategy on trauma. Retrieved August 28, 2024, from <https://www.mqmentalhealth.org/mq-joins-calls-for-a-public-health-strategy-on-trauma/>
- Downs, J., Gilbert, R., Hayes, R. D., Hotopf, M., & Ford, T. (2017). Linking health and education data to plan and evaluate services for children. *Archives of Disease in Childhood*, 102(7), 599–602.
<https://doi.org/10.1136/archdischild-2016-311656>
- Dyxhoorn, J., Fischer, L., Bayliss, B., Brayne, C., Crosby, L., Galvin, B., ... Walters, K. (2022). Conceptualising public mental health: development of a conceptual framework for public mental health. *BMC Public Health*, 22(1), 1–15. <https://doi.org/10.1186/s12889-022-13775-9>
- Early Intervention Foundation. (2018). *Realising the potential of early intervention*. Early Intervention Foundation. Retrieved from <https://www.eif.org.uk/report/realising-the-potential-of-early-intervention>
- Early Intervention Foundation. (2021). What is early intervention? Retrieved January 13, 2021, from <https://www.eif.org.uk/why-it-matters/what-is-early-intervention>
- Ehlers, A., & Clark, D. M. (2000). A cognitive model of posttraumatic stress disorder. *Behaviour Research and Therapy*, 38(4), 319–345. [https://doi.org/https://doi.org/10.1016/S0005-7967\(99\)00123-0](https://doi.org/10.1016/S0005-7967(99)00123-0)
- Essex, M. J., Kraemer, H. C., Armstrong, J. M., Boyce, W. T., Goldsmith, H. H., Klein, M. H., ... Kupfer, D. J. (2006). Exploring risk factors for the emergence of children’s mental health problems. *Archives of General Psychiatry*, 63(11), 1246–1256.
<https://doi.org/10.1001/archpsyc.63.11.1246>
- Evans, A. (2022). *Impact of childhood health and household experiences on educational attainment: Analysis using administrative data*. Cardiff University.
- Everson-Hock, E. S., Jones, R., Guillaume, L., Clapton, J., Duenas, A., Goyder, E., ... Swann, C. (2011). Supporting the transition of looked-after young people to independent living: a systematic

- review of interventions and adult outcomes. *Child: Care, Health & Development*, 37(6), 767–779. <https://doi.org/10.1111/j.1365-2214.2011.01287.x>
- Everson-Hock, E. S., Jones, R., Guillaume, L., Clapton, J., Goyder, E., Chilcott, J., ... Swann, C. (2012). The effectiveness of training and support for carers and other professionals on the physical and emotional health and well-being of looked-after children and young people: a systematic review. *Child: Care, Health & Development*, 38(2), 162–174. <https://doi.org/10.1111/j.1365-2214.2011.01247.x>
- Felitti, V. J., Anda, R. F., Nordenberg, D., Williamson, D. F., Spitz, A. M., Edwards, V., ... Marks, J. S. (1998). Relationship of childhood abuse and household dysfunction to many of the leading causes of death in adults: The Adverse Childhood Experiences (ACE) Study. *American Journal of Preventive Medicine*, 14(4), 245–258. <https://doi.org/10.1016/j.amepre.2019.04.001>
- Filkin, G., Ardern, K., Bethell, J., Buck, D., Corrigan, P., Griffiths, S., ... The King's Fund. (2023). A Covenant for Health: Policies and partnerships to improve our national health in 5 to 10 years, (July).
- Finkelhor, D., Shattuck, A., Turner, H., & Hamby, S. (2013). Improving the adverse childhood experiences study scale. *JAMA Pediatrics*, 167(1), 70–75.
- Ford, J., Sowden, A. S., Olivera, B. J., Bambra, C. C., Gimson, D. A., F, E. R. A., ... Olivera, J. (2021). Policy: Transforming health systems to reduce health inequalities. *Future Healthcare Journal*, 8(2), 1–6. <https://doi.org/10.7861/fhj.2021-0018>
- Ford, D. V., Jones, K. H., Verplancke, J. P., Lyons, R. A., John, G., Brown, G., ... Leake, K. (2009). The SAIL Databank: Building a national architecture for e-health research and evaluation. *BMC Health Services Research*, 9, 1–12. <https://doi.org/10.1186/1472-6963-9-157>
- Foster, H., Brooks-Gunn, J., & Martin, A. (2007). Poverty/socioeconomic status and exposure to violence in the lives of children and adolescents. In D. J. Flannery, A. T. Vazsonyi, & I. D. Waldman (Eds.), *The Cambridge handbook of violent behavior and aggression*. (pp. 664–687). New York, NY: Cambridge University Press. <https://doi.org/10.1017/CBO9780511816840.036>
- Fraser, A., Macdonald-wallis, C., Tilling, K., Boyd, A., Golding, J., Davey smith, G., ... Lawlor, D. A. (2013). Cohort profile: The avon longitudinal study of parents and children: ALSPAC mothers cohort. *International Journal of Epidemiology*, 42(1), 97–110. <https://doi.org/10.1093/ije/dys066>
- Fraser, J. G., Lloyd, S., Murphy, R., Crowson, M., Zolotor, A. J., Coker-Schwimmer, E., & Viswanathan, M. (2013). A comparative effectiveness review of parenting and trauma-focused interventions for children exposed to maltreatment. *Journal of Developmental and Behavioral Pediatrics*, 34(5), 353–368. <https://doi.org/10.1097/DBP.0b013e31828a7dfc>

- Gadd, C. (2020). Management and Supervision Tool (MaST). Retrieved August 8, 2024, from <https://nhsaccelerator.com/innovation/management-and-supervision-tool-mast/>
- Galvin, E., O'Donnell, R., Breman, R., Avery, J., Mousa, A., Halfpenny, N., & Skouteris, H. (2022). Interventions and Practice Models for Improving Health and Psychosocial Outcomes for Children in Residential Out-of-Home Care: Systematic Review. *Australian Social Work*, 75(1), 33–47. <https://doi.org/10.1080/0312407X.2020.1856394>
- GBD 2019 Mental Health Disorders Collaborators. (2022). Global, regional, and national burden of 12 mental disorders in 204 countries and territories, 1990–2019: a systematic analysis for the Global Burden of Disease Study 2019. *The Lancet Psychiatry*, 9(2), 137–150. [https://doi.org/10.1016/S2215-0366\(21\)00395-3](https://doi.org/10.1016/S2215-0366(21)00395-3)
- Geeraert, L., Van den Noortgate, W., Grietens, H., & Onghena, P. (2004). The Effects of Early Prevention Programs for Families With Young Children At Risk for Physical Child Abuse and Neglect: A Meta-Analysis. *Child Maltreatment*, 9(3), 277–291. <https://doi.org/10.1177/1077559504264265>
- Genomics England. (2024). Newborn Genomes Programme: Delivering the NHS-embedded Generation Study. Retrieved September 28, 2024, from <https://www.genomicsengland.co.uk/initiatives/newborns>
- Gentry, S. V., & Paterson, B. A. (2021). Does screening or routine enquiry for adverse childhood experiences (ACEs) meet criteria for a screening programme? A rapid evidence summary. *Journal of Public Health (Oxford, England)*. <https://doi.org/https://dx.doi.org/10.1093/pubmed/fdab238>
- Gerhard, T. (2008). Bias: Considerations for research practice. *American Journal of Health-System Pharmacy*, 65(22), 2159–2168. <https://doi.org/10.2146/ajhp070369>
- Giano, Z., Wheeler, D. L., & Hubach, R. D. (2020). The frequencies and disparities of adverse childhood experiences in the U.S. *BMC Public Health*, 20(1), 1–12. <https://doi.org/10.1186/s12889-020-09411-z>
- Google. (2023). Google Sheets [Computer application]. <https://www.google.com/sheets/about/>.
- Gopnik, A., Meltzoff, A. N., & Kuhl, P. K. (1999). *The scientist in the crib: Minds, brains, and how children learn*. William Morrow & Co.
- Graham, K. A., Blissett, J., Antoniou, E. E., Zeegers, M. P., & McCleery, J. P. (2018). Effects of maternal depression in the Still-Face Paradigm: A meta-analysis. *Infant Behavior and Development*, 50(June 2017), 154–164. <https://doi.org/10.1016/j.infbeh.2017.12.001>
- Grath-Lone, L. M., Libuy, N., Etoori, D., Blackburn, R., Gilbert, R., & Harron, K. (2021). Ethnic bias in data linkage. *The Lancet Digital Health*, 3(6), e339. <https://doi.org/10.1016/S2589->

- Gronholm, P. C., Nye, E., & Michelson, D. (2018). Stigma related to targeted school-based mental health interventions: A systematic review of qualitative evidence. *Journal of Affective Disorders, 240*(March), 17–26. <https://doi.org/10.1016/j.jad.2018.07.023>
- Grube, W. A., & Liming, K. W. (2018). Attachment and biobehavioral catch-up: A systematic review. *Infant Mental Health Journal, 39*(6), 656–673. <https://doi.org/10.1002/imhj.21745>
- Gunlicks, M. L., & Weissman, M. M. (2008). Change in child psychopathology with improvement in parental depression: a systematic review. *Journal of the American Academy of Child & Adolescent Psychiatry, 47*(4), 379–389. <https://doi.org/10.1097/CHI.0b013e3181640805>
- Guterman, N. B., Banman, A., & Bellamy, J. L. (2018). Promoting father involvement in early home visiting services for vulnerable families: Findings from a pilot study of “Dads matter.” *Child Abuse and Neglect, 76*, 261–272. <https://doi.org/http://dx.doi.org/10.1016/j.chiabu.2017.10.017>
- Gutterswijk, R. V., Kuiper, C. H. Z., Lautan, N., Kunst, E. G., van der Horst, F. C. P., Stams, G. J. J. M., & Prinzie, P. (2020). The outcome of non-residential youth care compared to residential youth care: A multilevel meta-analysis. *Children and Youth Services Review, 113*(104950), 1–11. <https://doi.org/10.1016/j.childyouth.2020.104950>
- Hambrick, E. P., Oppenheim-Weller, S., N’zi, A. M., & Taussig, H. N. (2016). Mental Health Interventions for Children in Foster Care: A Systematic Review. *Children and Youth Services Review, 70*, 65–77. <https://doi.org/10.1016/j.childyouth.2016.09.002>
- Hardt, J., & Rutter, M. (2004). Validity of adult retrospective reports of adverse childhood experiences: Review of the evidence. *Journal of Child Psychology and Psychiatry and Allied Disciplines, 45*(2), 260–273. <https://doi.org/10.1111/j.1469-7610.2004.00218.x>
- Harold, G. T., & Sellers, R. (2018). Annual Research Review: Interparental conflict and youth psychopathology: an evidence review and practice focused update. *Journal of Child Psychology and Psychiatry*. Retrieved from https://ezp.lib.cam.ac.uk/login?url=https://search.proquest.com/docview/2017690438?accountid=9851&bdid=7112&_bd=dNRv10biBsj5cipdTfKlzU8bp2E%3D
- Harris, P. A., Taylor, R., Minor, B. L., Elliott, V., Fernandez, M., O’Neal, L., ... Kirby, J. (2019). The REDCap consortium: building an international community of software platform partners. *Journal of Biomedical Informatics, 95*, 103208.
- Harris, P. A., Taylor, R., Thielke, R., Payne, J., Gonzalez, N., & Conde, J. G. (2009). Research electronic data capture (REDCap)—a metadata-driven methodology and workflow process for providing translational research informatics support. *Journal of Biomedical Informatics, 42*(2), 377–381.

- Harron, K., Dibben, C., Boyd, J., Hjern, A., Azimaee, M., Barreto, M. L., & Goldstein, H. (2017). Challenges in administrative data linkage for research. *Big Data & Society*, 4(2), 2053951717745678–2053951717745678. <https://doi.org/10.1177/2053951717745678>
- Harron, K., Wade, A., Gilbert, R., Muller-Pebody, B., & Goldstein, H. (2014). Evaluating bias due to data linkage error in electronic healthcare records. *BMC Medical Research Methodology*, 14(1). <https://doi.org/10.1186/1471-2288-14-36>
- Hart, L. M., Damiano, S. R., Chittleborough, P., Paxton, S. J., & Jorm, A. F. (2014). Parenting to prevent body dissatisfaction and unhealthy eating patterns in preschool children: A Delphi consensus study. *Body Image*, 11(4), 418–425. <https://doi.org/10.1016/j.bodyim.2014.06.010>
- Havinga, P. J., Maciejewski, D. F., Hartman, C. A., Hillegers, M. H. J., Schoevers, R. A., & Penninx, B. W. J. H. (2021). Prevention programmes for children of parents with a mood/anxiety disorder: Systematic review of existing programmes and meta-analysis of their efficacy. *The British Journal of Clinical Psychology*, 60(2), 212–251. <https://doi.org/10.1111/bjc.12277>
- Health Data Research UK (HDR UK). (2024). What We Do. Retrieved July 9, 2024, from <https://www.hdruk.ac.uk/about-us/what-we-do/>
- Healthwatch. (2017). Raising awareness of the experiences of homeless people. Retrieved August 18, 2024, from <https://www.healthwatch.co.uk/news/2017-02-03/raising-awareness-experiences-homeless-people>
- Heckman, J. J. (2012). The Heckman Equation. *Www.Heckmanequation.Org*, 1–2. Retrieved from www.heckmanequation.org
- Heerde, J. A., Hemphill, S. A., & Scholes-Balog, K. E. (2018). The impact of transitional programmes on post-transition outcomes for youth leaving out-of-home care: a meta-analysis. *Health & Social Care in the Community*, 26(1), e15–e30. <https://doi.org/http://dx.doi.org/10.1111/hsc.12348>
- Hemkens, L. G., Contopoulos-Ioannidis, D. G., & Ioannidis, J. P. A. (2016). Routinely collected data and comparative effectiveness evidence: promises and limitations. *CMAJ: Canadian Medical Association Journal*, 188(8), E158–E164. <https://doi.org/10.1503/cmaj.150653>
- Herbert, J. L., & Bromfield, L. (2016). Evidence for the Efficacy of the Child Advocacy Center Model: A Systematic Review. *Trauma, Violence & Abuse*, 17(3), 341–357. <https://doi.org/10.1177/1524838015585319>
- Hermenau, K., Goessmann, K., Rygaard, N. P., Landolt, M. A., & Hecker, T. (2017). Fostering Child Development by Improving Care Quality: A Systematic Review of the Effectiveness of Structural Interventions and Caregiver Trainings in Institutional Care. *Trauma Violence & Abuse*, 18(5), 544–561. <https://doi.org/10.1177/1524838016641918>

- Hesse, M., Thylstrup, B., Seid, A. K., & Skogen, J. C. (2020). Suicide among people treated for drug use disorders: A Danish national record-linkage study. *BMC Public Health*, 20(1), 1–9. <https://doi.org/10.1186/s12889-020-8261-4>
- Hippisley-Cox, J., Coupland, C., Vinogradova, Y., Robson, J., Minhas, R., Sheikh, A., & Brindle, P. (2008). Predicting cardiovascular risk in England and Wales: Prospective derivation and validation of QRISK2. *Bmj*, 336(7659), 1475–1482. <https://doi.org/10.1136/bmj.39609.449676.25>
- HM Government. (2021). *The Best Start for Life - A Vision for the 1,001 Critical Days: The Early Years Healthy Development Review Report*. London, UK. Retrieved from <https://www.gov.uk/government/publications/the-best-start-for-life-a-vision-for-the-1001-critical-days>
- Holmusk. (2024). Advancing the management of mental healthcare. Retrieved August 8, 2024, from <https://holmusk.co.uk/>
- Hossain, M. E., Khan, A., Moni, M. A., & Uddin, S. (2019). Use of electronic health data for disease prediction: A comprehensive literature review. *IEEE/ACM Transactions on Computational Biology and Bioinformatics*, 18(2), 745–758.
- House of Commons: Health and Social Care Committee. (2019). *First 1000 Days of Life: Thirteenth Report of Session 2017-19*. Retrieved from <https://publications.parliament.uk/pa/cm201719/cmselect/cmhealth/1496/1496.pdf>
- Houtepen, L. C., Heron, J., Suderman, M. J., Tilling, K., & Howe, L. D. (2018). Adverse childhood experiences in the children of the avon longitudinal study of parents and children (ALSPAC). *Wellcome Open Research*, 3(106), 1–9. <https://doi.org/10.12688/wellcomeopenres.14716.1>
- Howarth, E., Moore, T. H. M., Welton, N. J., Lewis, N., Stanley, N., MacMillan, H., ... Feder, G. (2016). IMPROving Outcomes for children exposed to domestic Violence (IMPROVE): an evidence synthesis. *Public Health Research*, 4(10), 1–378. <https://doi.org/10.3310/phr04100>
- Howarth, E., Vainre, M., Humphrey, A., Lombardo, C., Hanafiah, A. N., Anderson, J. K., & Jones, P. B. (2019). Delphi study to identify key features of community-based child and adolescent mental health services in the East of England. *BMJ Open*, 9(6). <https://doi.org/10.1136/bmjopen-2018-022936>
- Hughes, C., Devine, R. T., Mesman, J., & Blair, C. (2020). Parental well-being, couple relationship quality, and children's behavioral problems in the first 2 years of life. *Development and Psychopathology*, 32(3), 935–944. <https://doi.org/10.1017/S0954579419000804>
- Hughes, K., Bellis, M. A., Hardcastle, K. A., Sethi, D., Butchart, A., Mikton, C., ... Dunne, M. P. (2017). The effect of multiple adverse childhood experiences on health: a systematic review and meta-

- analysis. *The Lancet Public Health*, 2(8), e356–e366.
- Hughes, K., Lowey, H., Quigg, Z., & Bellis, M. A. (2016). Relationships between adverse childhood experiences and adult mental well-being: Results from an English national household survey. *BMC Public Health*, 16(1), 1–11. <https://doi.org/10.1186/s12889-016-2906-3>
- Hughes, M., & Tucker, W. (2018). Poverty as an Adverse Childhood Experience. *North Carolina Medical Journal*, 79(2), 124–126.
- Huxley, P. (1996). Mental illness in the community: The Goldberg-Huxley model of the pathway to psychiatric care. *Nordic Journal of Psychiatry*, 50(sup37), 47–53.
<https://doi.org/10.3109/08039489609099730>
- Inclusive Data Taskforce. (2021). *Leaving no-one behind: How can we be more inclusive in our data – Executive Summary*. Office for National Statistics. Retrieved from <https://uksa.statisticsauthority.gov.uk/publication/leaving-no-one-behind-how-can-we-be-more-inclusive-in-our-data-executive-summary/pages/2/>
- Indrayani, T., Palutturi, S., Amiruddin, R., Bintara Birawida, A., Widowati, R., Rukmaini, R., & Owildan, W. B. (2020). The development of T-CBT model to improve the competence of midwives in prevention depression of sexual violence victims. *Indian Journal of Public Health Research and Development*, 11(2), 2607–2612. <https://doi.org/10.37506/v11/i2/2020/ijphrd/195224>
- Information Commissioner’s Office. (2023). A guide to the data protection principles.
- Jackson, S., Newall, E., & Backett-Milburn, K. (2015). Children’s narratives of sexual abuse. *Child and Family Social Work*, 20(3), 322–332. <https://doi.org/10.1111/cfs.12080>
- James, S., Alemi, Q., & Zepeda, V. (2013). Effectiveness and implementation of evidence-based practices in residential care settings. *Children and Youth Services Review*, 35(4), 642–656. <https://doi.org/10.1016/j.childyouth.2013.01.007>
- John, A., McGregor, J., Marchant, A., Del Pozo-Baños, M., Farr, I., Nurmatov, U., ... Naughton, A. (n.d.). (In Press) Case-finding for childhood maltreatment in routinely collected data: an external validation study using a clinically assessed hospital-based cohort of suspected cases. *BMC Health Informatics*.
- John, Ann, Friedmann, Y., DelPozo-Banos, M., Frizzati, A., Ford, T., & Thapar, A. (2021). Association of school absence and exclusion with recorded neurodevelopmental disorders, mental disorders, or self-harm: a nationwide, retrospective, electronic cohort study of children and young people in Wales, UK. *The Lancet Psychiatry*, 0366(21), 1–12. [https://doi.org/10.1016/S2215-0366\(21\)00367-9](https://doi.org/10.1016/S2215-0366(21)00367-9)
- John, Ann, Friedmann, Y., DelPozo-Banos, M., Frizzati, A., Ford, T., & Thapar, A. (2022). Association of school absence and exclusion with recorded neurodevelopmental disorders, mental disorders,

- or self-harm: a nationwide, retrospective, electronic cohort study of children and young people in Wales, UK. *The Lancet Psychiatry*, 9(1), 23–34. [https://doi.org/10.1016/S2215-0366\(21\)00367-9](https://doi.org/10.1016/S2215-0366(21)00367-9)
- John, Ann, McGregor, J., Marchant, A., DelPozo-Baños, M., Farr, I., Nurmatov, U., ... Naughton, A. (2023). An external validation of coding for childhood maltreatment in routinely collected primary and secondary care data. *Scientific Reports*, 13(1), 8138.
- Jones, A. (2009). *Second Serious Case Review Overview Report relating to Peter Connelly*. Retrieved from https://assets.publishing.service.gov.uk/media/5a8155a4e5274a2e8ab536d2/second_serious_case_overview_report_relating_to_peter_connelly_dated_march_2009.pdf
- Jones, K. H., Ford, D. V., & Lyons, R. A. (2017). *The SAIL Databank: 10 years of spearheading data privacy and research utility, 2007-2017*.
- Jones, K. H., Ford, D. V., Thompson, S., & Lyons, R. A. (2019). A profile of the SAIL databank on the UK secure research platform. *International Journal of Population Data Science*, 4(2). <https://doi.org/10.23889/ijpds.v4i2.1134>
- Jones, L. A., Nelder, J. R., Fryer, J. M., Alsop, P. H., Geary, M. R., Prince, M., & Cardinal, R. N. (2022). Public opinion on sharing data from health services for clinical and research purposes without explicit consent: An anonymous online survey in the UK. *BMJ Open*, 12(4). <https://doi.org/10.1136/bmjopen-2021-057579>
- Journot-Reverbel, K., Raynaud, J.-P., Bui, E., & Revet, A. (2017). Support groups for children and adolescents bereaved by suicide: Lots of interventions, little evidence. *Psychiatry Research*, 250, 253–255. <https://doi.org/10.1016/j.psychres.2017.01.077>
- Kanine, R. M., Tunno, A. M., Jackson, Y., & O'Connor, B. M. (2015). Therapeutic Day Treatment for Young Maltreated Children: A Systematic Literature Review. *Journal of Child and Adolescent Trauma*, 8, 187–199. <https://doi.org/10.1007/s40653-015-0053-0>
- Kemmis-Riggs, J., Dickes, A., & McAloon, J. (2018). Program Components of Psychosocial Interventions in Foster and Kinship Care: A Systematic Review. *Clinical Child and Family Psychology Review*, 21, 13–40. <https://doi.org/http://dx.doi.org/10.1007/s10567-017-0247-0>
- Kerr, L., & Cossar, J. (2014). Attachment Interventions with Foster and Adoptive Parents: A Systematic Review. *Child Abuse Review*, 23(6), 426–439. <https://doi.org/10.1002/car.2313>
- Kessler, R. C., Berglund, P., Demler, O., Jin, R., Merikangas, K. R., & Walters, E. E. (2005). Lifetime prevalence and age-of-onset distributions of DSM-IV disorders in the national comorbidity survey replication. *Archives of General Psychiatry*, 62(6), 593–602. <https://doi.org/10.1001/archpsyc.62.6.593>

- Kinsey, D., & Schlösser, A. (2013). Interventions in foster and kinship care: A systematic review. *Clinical Child Psychology & Psychiatry*, 18(3), 429–463.
<https://doi.org/10.1177/1359104512458204>
- Knight, H. E., Deeny, S. R., Dreyer, K., Engmann, J., Mackintosh, M., Raza, S., ... Steventon, A. (2021). Challenging racism in the use of health data. *The Lancet Digital Health*.
[https://doi.org/10.1016/S2589-7500\(21\)00019-4](https://doi.org/10.1016/S2589-7500(21)00019-4)
- Kreps, G. L. (2017). Stigma and the reluctance to address mental health issues in minority communities. *Journal of Family Strengths*, 17(1), 1–13. Retrieved from
<https://digitalcommons.library.tmc.edu/jfs/vol17/iss1/3>
- Lacey, R. E., Howe, L. D., Kelly-Irving, M., Bartley, M., & Kelly, Y. (2020). The Clustering of Adverse Childhood Experiences in the Avon Longitudinal Study of Parents and Children: Are Gender and Poverty Important? *Journal of Interpersonal Violence*, 1–19.
<https://doi.org/10.1177/0886260520935096>
- Lacey, R. E., & Minnis, H. (2020). Practitioner Review: Twenty years of research with adverse childhood experience scores – Advantages, disadvantages and applications to practice. *Journal of Child Psychology and Psychiatry*, 61(2), 116–130.
<https://doi.org/http://dx.doi.org/10.1111/jcpp.13135>
- Låftman, S. B., Modin, B., & Östberg, V. (2013). Cyberbullying and subjective health. A large-scale study of students in Stockholm, Sweden. *Children and Youth Services Review*, 35(1), 112–119.
<https://doi.org/10.1016/j.childyouth.2012.10.020>
- Lai, E. T. C., Wickham, S., Law, C., Whitehead, M., Barr, B., & Taylor-Robinson, D. (2019). Poverty dynamics and health in late childhood in the UK: Evidence from the Millennium Cohort Study. *Archives of Disease in Childhood*, 104(11), 1049–1055. <https://doi.org/10.1136/archdischild-2018-316702>
- Laming, H. (2003). *The Victoria Climbié Inquiry: Report of an Inquiry*. London: The Stationery Office. London. Retrieved from
<https://assets.publishing.service.gov.uk/media/5a7c5edeed915d696ccfc51b/5730.pdf>
- Lee, A., Elliott, M., Scourfield, J., Bedston, S., Broadhurst, K., Ford, D. V., & Griffiths, L. J. (2022). Data resource: Children receiving care and support and children in need, administrative records in Wales. *International Journal of Population Data Science*.
- Leijten, P., Gardner, F., Melendez-Torres, G. J., Weeland, J., Hutchings, J., Landau, S., ... Scott, S. (2019). Co-occurring change in children’s conduct problems and maternal depression: Latent class individual participant data meta-analysis of the Incredible Years parenting program. *Development and Psychopathology*, 31(5), 1851–1862.

<https://doi.org/10.1017/S0954579419001068>

- Lester, S., Lorenc, T., Sutcliffe, K., Khatwa, M., Stansfield, C., Sowden, A., & Thomas, J. (2019). *What helps to support people affected by Adverse Childhood Experiences? A review of evidence*. London: EPPI-Centre, Social Science Research Unit, UCL Institute of Education, University College London. Retrieved from <http://eppi.ioe.ac.uk/>
- Letourneau, N. L., Dennis, C., Cosic, N., & Linder, J. (2017). The effect of perinatal depression treatment for mothers on parenting and child development: A systematic review. *Depression and Anxiety*, 34(10), 928–966. <https://doi.org/10.1002/da.22687>
- Leung, D. Y. L., Chan, A. C. Y., & Ho, G. W. K. (2020). Resilience of Emerging Adults After Adverse Childhood Experiences: A Qualitative Systematic Review. *Trauma, Violence & Abuse*, 1524838020933865. <https://doi.org/http://dx.doi.org/10.1177/1524838020933865>
- Liabo, K., Gray, K., & Mulcahy, D. (2013). A systematic review of interventions to support looked-after children in school. *Child & Family Social Work*, 18(3), 341–353. <https://doi.org/10.1111/j.1365-2206.2012.00850.x>
- Lim, S. L. (2019). Living in lack: How poverty affects the mental health of urban youth. *Medical Journal of Malaysia*, 74(Supplement 2), 109. Retrieved from <http://www.e-mjm.org/2019/v74s2/v74-Supp-2-2019.pdf>
- Liming, K. W., & Grube, W. A. (2018). Wellbeing Outcomes for Children Exposed to Multiple Adverse Experiences in Early Childhood: A Systematic Review. *Child & Adolescent Social Work Journal*, 35(4), 317–335. <https://doi.org/http://dx.doi.org/10.1007/s10560-018-0532-x>
- Lindstrom Johnson, S., Elam, K., Rogers, A. A., & Hilley, C. (2018). A Meta-Analysis of Parenting Practices and Child Psychosocial Outcomes in Trauma-Informed Parenting Interventions after Violence Exposure. *Prevention Science*, 19(7), 927–938. <https://doi.org/http://dx.doi.org/10.1007/s11121-018-0943-0>
- Loechner, J., Starman, K., Galuschka, K., Tamm, J., Schulte-Körne, G., Rubel, J., & Platt, B. (2018). Preventing depression in the offspring of parents with depression: A systematic review and meta-analysis of randomized controlled trials. *Clinical Psychology Review*, 60, 1–14. <https://doi.org/10.1016/j.cpr.2017.11.009>
- Lorenc, T., Lester, S., Sutcliffe, K., Stansfield, C., & Thomas, J. (2020). Interventions to support people exposed to adverse childhood experiences: Systematic review of systematic reviews. *BMC Public Health*, 20(1), 1–10. <https://doi.org/10.1186/s12889-020-08789-0>
- Lowthian, E., Anthony, R., Evans, A., Daniel, R., Long, S., Bandyopadhyay, A., ... Paranjothy, S. (2021). Adverse childhood experiences and child mental health: an electronic birth cohort study. *BMC Medicine*, 19(1), 1–13. <https://doi.org/10.1186/s12916-021-02045-x>

- Lyons, R. A., Jones, K. H., John, G., Brooks, C. J., Verplancke, J. P., Ford, D. V., ... Leake, K. (2009). The SAIL databank: Linking multiple health and social care datasets. *BMC Medical Informatics and Decision Making*, 9(1), 1–8. <https://doi.org/10.1186/1472-6947-9-3>
- Maclean, M. J., Sims, S., O'Donnell, M., & Gilbert, R. (2016). Out-of-home Care versus In-home Care for Children Who Have Been Maltreated: A Systematic Review of Health and Wellbeing Outcomes. *Child Abuse Review*, 25(4), 251–272. <https://doi.org/10.1002/car.2437>
- Maddocks, P. (2013). *A Serious Case Review: Hamzah Khan: The Overview Report*. Retrieved from <https://www.saferbradford.co.uk/media/mx4nkor4/2013-bradford-hamzah-khan-overview.pdf>
- Marcellus, L., MacKinnon, K., Gordon, C., & Shaw, L. (2021). Interventions and programs that support the health and development of infants with prenatal substance exposure in foster care: a scoping review. *JBI Evidence Synthesis*, 19(8), 1844–1886. <https://doi.org/10.11124/JBIES-20-00071>
- Marie-Mitchell, A., & Kostolansky, R. (2019). A Systematic Review of Trials to Improve Child Outcomes Associated With Adverse Childhood Experiences. *American Journal of Preventive Medicine*, 56(5), 756–764. <https://doi.org/10.1016/j.amepre.2018.11.030>
- Marmot, M. (2005). Social determinants of health inequalities. *The Lancet*, 365(9464), 1099–1104.
- Marmot, M. (2010). Marmot Review: Fair Society, Healthy Lives. Retrieved from www.ucl.ac.uk/marmotreview
- Marmot, M. (2012). Fair society, healthy lives. *Public Health*, 126(SUPPL.1), S4. <https://doi.org/10.1016/j.puhe.2012.05.014>
- Marmot, M., Friel, S., Bell, R., Houweling, T. A., & Taylor, S. (2008). Closing the gap in a generation: health equity through action on the social determinants of health. *The Lancet*, 372(9650), 1661–1669. [https://doi.org/10.1016/S0140-6736\(08\)61690-6](https://doi.org/10.1016/S0140-6736(08)61690-6)
- McDaid, D., & Park, A.-L. (2022). The economic case for investing in mental health prevention Summary, (February), 1–20. Retrieved from [https://www.mentalhealth.org.uk/sites/default/files/MHF Investing in_Prevention Report.pdf](https://www.mentalhealth.org.uk/sites/default/files/MHF%20Investing%20in%20Prevention%20Report.pdf)
- McFadden, A., Siebelt, L., Gavine, A., Atkin, K., Bell, K., Innes, N., ... MacGillivray, S. (2018). Gypsy, Roma and Traveller access to and engagement with health services: a systematic review. *The European Journal of Public Health*, 28(1), 74–81.
- McGee, G., Haneuse, S., Coull, B. A., Weisskopf, M. G., & Rotem, R. S. (2022). On the nature of informative presence: Bias in analyses of electronic health records. *Epidemiology*, 33(1), 105–113. <https://doi.org/10.1097/EDE.0000000000001432>
- McKenzie, K., & Scott, D. A. (2011). Using routinely collected hospital data for child maltreatment surveillance: issues, methods and patterns. *BMC Public Health*, 11(1), 1–10.

- McKenzie, K., Scott, D. A., Waller, G. S., & Campbell, M. (2011). Reliability of routinely collected hospital data for child maltreatment surveillance. *BMC Public Health*, 11(1), 1–8.
- Meehan, A. J., Lewis, S. L., Fazel, S., Fusar-Poli, P., Steyerberg, E. W., Stahl, D., & Danese, A. (2022). Clinical prediction models in psychiatry: a systematic review of progress and limitations to date, (July 2021). <https://doi.org/10.1038/s41380-022-01528-4>
- Melis, G., Bedston, S., Akbari, A., Bennett, D., Lee, A., Lowthian, E., ... Taylor-Robinson, D. (2023). Impact of socio-economic conditions and perinatal factors on risk of becoming a child looked after: a whole population cohort study using routinely collected data in Wales. *Public Health*, 224, 215–223. <https://doi.org/10.1016/j.puhe.2023.09.001>
- Mental Health Taskforce. (2016). *The Five Year Forward View for Mental Health*. Retrieved from <https://www.england.nhs.uk/wp-content/uploads/2016/02/Mental-Health-Taskforce-FYFV-final.pdf>
- Merrick, M. T., Ford, D. C., Ports, K. A., & Guinn, A. S. (2018). Prevalence of Adverse Childhood Experiences from the 2011-2014 Behavioral Risk Factor Surveillance System in 23 States. *JAMA Pediatrics*, 172(11), 1038–1044. <https://doi.org/10.1001/jamapediatrics.2018.2537>
- Mitra, R., & Hodes, M. (2019). Prevention of psychological distress and promotion of resilience amongst unaccompanied refugee minors in resettlement countries. *Child: Care, Health and Development*, 45(2), 198–215. <https://doi.org/10.1111/cch.12640>
- Moher, D., Liberati, A., Tetzlaff, J., Altman, D. G., Altman, D., Antes, G., ... Tugwell, P. (2009). Preferred reporting items for systematic reviews and meta-analyses: The PRISMA statement. *PLoS Medicine*, 6(7). <https://doi.org/10.1371/journal.pmed.1000097>
- Moher, D., Shamseer, L., Clarke, M., Ghersi, D., Liberati, A., Petticrew, M., ... PRISMA-P Group. (2015). Preferred reporting items for systematic review and meta-analysis protocols (PRISMA-P) 2015 statement. *Systematic Reviews*, 4(1), 1–9.
- Montgomery, P., Gardner, F., Bjornstad, G., & Ramchandani, P. (2009). *Systematic reviews of interventions following physical abuse: helping practitioners and expert witnesses improve the outcomes of child abuse*. Retrieved from <https://www.researchgate.net/publication/237416324>
- Moore, A., Micklem, G., Cardinal, R., Thomson, B., Tammuz, N., Sallamuddin, T., ... Evans, T. (2022). *FAIR TREATMENT: Federated analytics and AI Research across TREs for Adolescent MENTAL health*. <https://doi.org/10.5281/zenodo.7085495>
- Morgan, K., Page, N., Brown, R., Long, S., Hewitt, G., Del Pozo-Banos, M., ... Moore, G. (2020). Sources of potential bias when combining routine data linkage and a national survey of secondary school-aged children: A record linkage study. *BMC Medical Research Methodology*,

- 20(1), 1–13. <https://doi.org/10.1186/s12874-020-01064-1>
- Morton, M. H., Kugley, S., Epstein, R., & Farrell, A. (2020). Interventions for youth homelessness: A systematic review of effectiveness studies. *Children and Youth Services Review*, 116, 1–13. <https://doi.org/10.1016/j.childyouth.2020.105096>
- MQ. (2017). *UK Mental Health Research Funding 2014–2017*. London. Retrieved from <https://www.mqmentalhealth.org/wp-content/uploads/UKMentalHealthResearchFunding2014-2017digital.pdf>
- Negriff, S. (2020). ACEs are not equal: Examining the relative impact of household dysfunction versus childhood maltreatment on mental health in adolescence. *Social Science & Medicine*, 245(112696), 1–19. <https://doi.org/https://doi.org/10.1016/j.socscimed.2019.112696>
- Nelson, C. A., Scott, R. D., Bhutta, Z. A., Harris, N. B., Danese, A., & Samara, M. (2020). Adversity in childhood is linked to mental and physical health throughout life. *BMJ (Clinical Research Ed.)*, 371(October), m3048. <https://doi.org/10.1136/bmj.m3048>
- Newlove-Delgado, T., Marcheselli, F., Williams, T., Mandalia, D., Davis, J., McManus, S., ... Ford, T. (2022). Mental Health of Children and Young People in England 2022. Retrieved from <https://digital.nhs.uk/data-and-information/publications/statistical/mental-health-of-children-and-young-people-in-england/2022-follow-up-to-the-2017-survey#>
- Newton, K., Taylor Buck, E., Weich, S., & Uttley, L. (2020). A review and analysis of the components of potentially effective perinatal mental health interventions for infant development and mother-infant relationship outcomes. *Development and Psychopathology*, 34(1), 37–54. <https://doi.org/10.1017/S0954579420001340>
- NHS England. (2023). Dealing with medical records for adopted patients: A guide for GP practices. Retrieved from <https://pcse.england.nhs.uk/sites/default/files/2023-08/adoption-medical-records-practice-guide.pdf>
- NHS England. (2024). Mental Health. Retrieved August 23, 2024, from <https://www.england.nhs.uk/mental-health/>
- NHS Providers. (2019). Mental Health Services: The Demand Challenge. Retrieved July 11, 2021, from <https://nhsproviders.org/mental-health-services-addressing-the-care-deficit/the-demand-challenge>
- Niccols, A., Milligan, K., Smith, A., Sword, W., Thabane, L., & Henderson, J. (2012). Integrated programs for mothers with substance abuse issues and their children: a systematic review of studies reporting on child outcomes. *Child Abuse & Neglect*, 36(4), 308–322. <https://doi.org/10.1016/j.chiabu.2011.10.007>
- NICE. (2013). Depression in Children and Young People – Evidence Update June 2013. National

Institute for Health and Care Excellence: Manchester.

- Nickerson, A., Bryant, R. A., Aderka, I. M., Hinton, D. E., & Hofmann, S. G. (2013). The impacts of parental loss and adverse parenting on mental health: Findings from the National Comorbidity Survey-Replication. *Psychological Trauma: Theory, Research, Practice, and Policy*, 5(2), 119.
- NIHR. (2020). *Improving inclusion of under-served groups in clinical research: Guidance from INCLUDE project*. UK. Retrieved from www.nihr.ac.uk/documents/improving-inclusion-of-under-served-groups-in-clinical-research-guidance-from-include-project/25435
- NIHR BioResource. (2025). D-CYPHR: DNA, Children + Young People's Health Resource. Retrieved June 23, 2024, from <https://www.bioresource.nihr.ac.uk/d-cyphr/>
- Nilsen, W., Johansen, S., Blaasvær, N., Hammerstrøm, K. T., & Berg, R. C. (2015). *Effect of Interventions Targeting Incarcerated Parents and Their Children* (Vol. 15–2015). Retrieved from https://www.ncbi.nlm.nih.gov/books/NBK390563/pdf/Bookshelf_NBK390563.pdf
- Nocon, A., Eberle-Sejari, R., Unterhitzberger, J., & Rosner, R. (2017). .The effectiveness of psychosocial interventions in war-traumatized refugee and internally displaced minors: systematic review and meta-analysis. *European Journal of Psychotraumatology*, 8(sup2). <https://doi.org/10.1080/20008198.2017.1388709>
- Noh, D. (2018). Psychological Interventions for Runaway and Homeless Youth. *Journal of Nursing Scholarship*, 50(5), 465–472. <https://doi.org/10.1111/jnu.12402>
- NSPCC. (2024). Statistics on child abuse. Retrieved August 15, 2024, from <https://learning.nspcc.org.uk/statistics-child-abuse>
- O'Hara, M. W., & Wisner, K. L. (2014). Perinatal mental illness: Definition, description and aetiology. *Best Practice and Research: Clinical Obstetrics and Gynaecology*, 28(1), 3–12. <https://doi.org/10.1016/j.bpobgyn.2013.09.002>
- O'Higgins, A., Ott, E. M., & Shea, M. W. (2018). What is the Impact of Placement Type on Educational and Health Outcomes of Unaccompanied Refugee Minors? A Systematic Review of the Evidence. *Clinical Child and Family Psychology Review*, 21(3), 354–365. <https://doi.org/10.1007/s10567-018-0256-7>
- Office for National Statistics. (2022). Population and household estimates, Wales: Census 2021. Retrieved July 17, 2024, from <https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates/bulletins/populationandhouseholdestimateswales/census2021>
- Oja, C., Edbom, T., Nager, A., Månsson, J., & Ekblad, S. (2020). Informing children of their parent's illness: A systematic review of intervention programs with child outcomes in all health care settings globally from inception to 2019. *PLoS ONE*, 15(5), 1–24.

- <https://doi.org/10.1371/journal.pone.0233696>
- Parkin, K., Crowley, R., Massou, E., Del Pozo Baños, M., Friedmann, Y., John, A., & Moore, A. (2023). *Towards Early Identification of Mental Health Problems in Children's Social Care*. Retrieved from <https://whatworks-csc.org.uk/wp-content/uploads/towards-early-identification-of-mental-health-problems-in-childrens-social-care.pdf>
- Pearce, L. A., Borschmann, R., Young, J. T., & Kinner, S. A. (2023). Advancing cross-sectoral data linkage to understand and address the health impacts of social exclusion: Challenges and potential solutions. *International Journal of Population Data Science*, 8(1), 1–14.
- Perez, C. C. (2019). *Invisible women: Exploring data bias in a world designed for men* (1st ed.). London: Penguin.
- Perry, R. C., Ford, T. J., O'Mahen, H., & Russell, A. E. (2021). Prioritising Targets for School-Based ADHD Interventions: A Delphi Survey. *School Mental Health*. <https://doi.org/10.1007/s12310-020-09408-4>
- Phillips, S. D., Gleeson, J. P., & Waites-Garrett, M. (2009). Substance-Abusing Parents in the Criminal Justice System: Does Substance Abuse Treatment Improve Their Children's Outcomes? *Journal of Offender Rehabilitation*, 48(2), 120–138. <https://doi.org/10.1080/10509670802640925>
- Piegenschke, K., Sihorsch, M., & Christiansen, H. (2019). Begleitete minderjährige Geflüchtete: Eine systematische Übersicht über psychologische Interventionen mit Familieneinbezug (Accompanied refugee minors: A systematic review of psychological interventions with family inclusion). *Kindheit Und Entwicklung: Zeitschrift Für Klinische Kinderpsychologie*, 28(3), 147–159. <https://doi.org/10.1026/0942-5403/a000285>
- Poli, C. F., Molgora, S., Marzotto, C., Facchin, F., & Cyr, F. (2017). Group Interventions for Children Having Separated Parents: A Systematic Narrative Review. *Journal of Divorce & Remarriage*, 58(8), 559–583. <https://doi.org/10.1080/10502556.2017.1345243>
- Poobalan, A. S., Aucott, L. S., Ross, L., Smith, W. C. S., Helms, P. J., & Williams, J. H. G. (2007). Effects of treating postnatal depression on mother-infant interaction and child development: Systematic review. *British Journal of Psychiatry*, 191, 378–386. <https://doi.org/10.1192/bjp.bp.106.032789>
- Popay, J., Roberts, H., Sowden, A., Petticrew, M., Arai, L., Rodgers, M., & Britten, N. (2006). Narrative Synthesis in Systematic Reviews: A Product from the ESRC Methods Programme. *ESRC Methods Programme*, (2006), 93. <https://doi.org/10.13140/2.1.1018.4643>
- QSR International Pty Ltd. (2018). NVivo (Version 12). Retrieved from <https://www.qsrinternational.com/nvivo-qualitative-data-analysis-software/home>
- Qualtrics. (2005). Qualtrics software (Version: December 2023). Provo, Utah, USA. Retrieved from

<https://www.qualtrics.com>

- Quinn, T. P., Jacobs, S., Senadeera, M., Le, V., & Coghlan, S. (2020). The three ghosts of medical AI: Can the black-box present deliver? *Artificial Intelligence in Medicine*, 124, 1–12.
<https://doi.org/10.1016/j.artmed.2021.102158>
- Radford, L., Corral, S., Bradley, C., Fisher, H., Bassett, C., Howat, N., & Collishaw, S. (2011). *Child abuse and neglect in the UK today*. NSPCC. London. Retrieved from
https://www.blackpoolsafeguarding.org.uk/assets/uploads/resources/Children/child_abuse_neglect_research_PDF_wdf84181.pdf
- Rayce, S. B., Rasmussen, I. S., Skovgaard Væver, M., & Pontoppidan, M. (2020). Effects of parenting interventions for mothers with depressive symptoms and an infant: Systematic review and meta-analysis. *BJPsych Open*, 6(e9), 1–10. <https://doi.org/10.1192/bjo.2019.89>
- Read, J., Hammersley, P., & Rudegeair, T. (2007). Why, when and how to ask about childhood abuse. *Advances in Psychiatric Treatment*, 13(2), 101–110. <https://doi.org/10.1192/apt.bp.106.002840>
- Rees, S., Fry, R., Davies, J., John, A., & Condon, L. (2023). Can routine data be used to estimate the mental health service use of children and young people living on Gypsy and Traveller sites in Wales? A feasibility study, 1–23. <https://doi.org/10.1371/journal.pone.0281504>
- Reidy, D. E., Niolon, P. H., Estefan, L. F., Kearns, M. C., D’Inverno, A. S., Marker, C. D., & Merrick, M. T. (2021). Measurement of Adverse Childhood Experiences: It Matters. *American Journal of Preventive Medicine*, 61(6), 821–830.
<https://doi.org/https://doi.org/10.1016/j.amepre.2021.05.043>
- Reupert, A. E., Cuff, R., Drost, L., Foster, K., van Doesum, K. T. M., & van Santvoort, F. (2013). Intervention programs for children whose parents have a mental illness: a review. *Medical Journal of Australia*, 199(3 Suppl), 18–22. <https://doi.org/10.5694/mja11.11145>
- Rizo, C. F., Macy, R. J., Ermentrout, D. M., & Johns, N. B. (2011). A review of family interventions for intimate partner violence with a child focus or child component. *Aggression and Violent Behavior*, 16(2), 144–166. <https://doi.org/10.1016/j.avb.2011.02.004>
- Roberts, L., Maxwell, N., Rees, P., Holland, S., & Forbes, N. (2016). Improving well-being and outcomes for looked after children in Wales: a context sensitive review of interventions. *Adoption and Fostering*, 40(4), 309–324. <https://doi.org/10.1177/0308575916675563>
- Rocks, S., & Tsiachristas, A. (2019). The UK doesn’t spend enough on the mental health of young people – we found out why. Retrieved August 7, 2024, from <https://theconversation.com/the-uk-doesnt-spend-enough-on-the-mental-health-of-young-people-we-found-out-why-124315>
- Rose, G. (1992). *Strategy of Preventive Medicine*. Oxford: Oxford University Press.
- Rose, G. (2001). Sick individuals and sick populations. *International Journal of Epidemiology*, 30(3),

- 427–432. <https://doi.org/10.1093/ije/30.3.427>
- Routen, A., Bodicoat, D., Willis, A., Treweek, S., Paget, S., & Khunti, K. (2022). Tackling the lack of diversity in cancer research. *British Journal of General Practice*, 72(722), 444–447. <https://doi.org/10.1242/dmm.050275>
- Rudin, C. (2019). Stop explaining black box machine learning models for high stakes decisions and use interpretable models instead. *Nature Machine Intelligence*, 1(5), 206–215. <https://doi.org/10.1038/s42256-019-0048-x>
- Ruff, S., McComb, J. L., Coker, C. J., & Sprenkle, D. H. (2010). Behavioral couples therapy for the treatment of substance abuse: a substantive and methodological review of O’Farrell, Fals-Stewart, and colleagues’ program of research. *Family Process*, 49(4), 439–456. <https://doi.org/10.1111/j.1545-5300.2010.01333.x>
- Rutter, A. (2021). The relevance of the adverse childhood experience international questionnaire to working children: Knowledge gaps and implications for policy makers. *Children*, 8(10). <https://doi.org/10.3390/children8100897>
- Sahle, B. W., Reavley, N. J., Li, W., Morgan, A. J., Jorm, A. F., Hui Yap, M. B., ... Jorm, A. F. (2021). The association between adverse childhood experiences and common mental disorders and suicidality: an umbrella review of systematic reviews and meta-analyses. *European Child and Adolescent Psychiatry*. <https://doi.org/http://dx.doi.org/10.1007/s00787-021-01745-2>
- Sahle, B. W., Reavley, N. J., Morgan, A. J., Yap, M. B. H., Reupert, A., & Jorm, A. F. (2021). A Delphi study to identify intervention priorities to prevent the occurrence and reduce the impact of adverse childhood experiences. *The Australian and New Zealand Journal of Psychiatry*, 48674211025717. <https://doi.org/https://dx.doi.org/10.1177/00048674211025717>
- Samaan, R. A. (2000). The influences of race, ethnicity, and poverty on the mental health of children. *Journal of Health Care for the Poor and Underserved*, 11(1), 100–110. <https://doi.org/10.1353/hpu.2010.0557>
- Satinsky, E. N., Kakuhikire, B., Baguma, C., Rasmussen, J. D., Ashaba, S., Cooper-Vince, C. E., ... Tsai, A. C. (2021). Adverse childhood experiences, adult depression, and suicidal ideation in rural Uganda: A cross-sectional, population-based study. *PLOS Medicine*, 18(5), e1003642. <https://doi.org/10.1371/journal.pmed.1003642>
- Saxena, S., Francis, N., & Sharland, M. (2012). Primary care of children: The unique role of GPs. *British Journal of General Practice*, 62(600), 340–341. <https://doi.org/10.3399/bjgp12X652166>
- SBU Assessments. (2017). *Interventions to improve foster children’s mental and physical health: A systematic review and assessment of the economic, social and ethical aspects*. Swedish Agency for Health Technology Assessment and Assessment of Social Services. Retrieved from

- http://www.sbu.se/contentassets/890c0a078ca342ef8f3f3df817acb4f2/interventions_improve_foster_childrens_mental_physical_health_2017_smf.pdf
- Scarpellini, G. (2020). IDoStatistics: Resources for Statistics and Meta-Analyses. Cohen's kappa free calculator. Retrieved from <https://idostatistics.com/cohen-kappa-free-calculator/>
- Schnitzer, P. G., Slusher, P. L., Kruse, R. L., & Tarleton, M. M. (2011). Identification of ICD codes suggestive of child maltreatment. *Child Abuse & Neglect*, 35(1), 3–17.
- Schoeler, T., Speed, D., Porcu, E., Pirastu, N., Pingault, J. B., & Kutalik, Z. (2023). Participation bias in the UK Biobank distorts genetic associations and downstream analyses. *Nature Human Behaviour*, 7, 1216–1227. <https://doi.org/10.1038/s41562-023-01579-9>
- Schoemaker, N. K., Wentholt, W. G. M., Goemans, A., Vermeer, H. J., Juffer, F., & Alink, L. R. A. (2020). A meta-analytic review of parenting interventions in foster care and adoption. *Development and Psychopathology*, 32(3), 1149–1172. <https://doi.org/10.1017/S0954579419000798>
- Schrader McMillan, A., Barlow, J., Stewart Brown, S., Carter, Y., Sidebotham, P., & Moli, P. (2008). *A systematic review of interventions for the secondary prevention and treatment of emotional abuse of children by primary carers*. Warwick Medical School, University of Warwick. Retrieved from <http://wrap.warwick.ac.uk/2906/>
- Scottish Government. (2017). *Young carers: Review of research and data*. Retrieved from <http://www.gov.scot/Resource/0051/00514848.pdf>
- Sederer, L. I. (2016). The social determinants of mental health. *Psychiatric Services*, 67(2), 234–235. <https://doi.org/10.1176/appi.ps.201500232>
- Seery, M. (2011). Resilience: A Silver Lining to Experiencing Adverse Life Events? *Current Directions in Psychological Science*, 20(6), 390–394.
- Sellgren, K. (2010). Baby Peter “was failed by all agencies.” Retrieved May 24, 2024, from <https://www.bbc.co.uk/news/education-11621391>
- Shah, N., & Marie-Mitchell, A. (2019). Socioeconomic factors impact the influence of adverse childhood experiences on health outcomes. *Journal of Investigative Medicine*, 67(1), 190. <https://doi.org/http://dx.doi.org/10.1136/jim-2018-000939.285>
- Shamseer, L., Moher, D., Clarke, M., Ghersi, D., Liberati, A., Petticrew, M., ... Stewart, L. A. (2015). PRISMA-P (Preferred Reporting Items for Systematic review and Meta-Analysis Protocols) 2015 checklist: recommended items to address in a systematic review protocol. *BMJ*. Retrieved from <http://www.bmj.com/content/bmj/349/bmj.g7647.full.pdf>
- Shamseer, L., Moher, D., Clarke, M., Ghersi, D., Liberati, A., Petticrew, M., ... Whitlock, E. (2015). Preferred reporting items for systematic review and meta-analysis protocols (prisma-p) 2015:

- Elaboration and explanation. *BMJ (Online)*, 349(February 2012), 1–25.
<https://doi.org/10.1136/bmj.g7647>
- Shea, B. J., Reeves, B. C., Wells, G., Thuku, M., Hamel, C., Moran, J., ... Henry, D. (2017a). AMSTAR 2: a critical appraisal tool for systematic reviews that include randomised or non-randomised studies of healthcare interventions, or both. *BMJ*, 21(358:j4008).
- Shea, B. J., Reeves, B. C., Wells, G., Thuku, M., Hamel, C., Moran, J., ... Henry, D. (2017b). Online Appendix 1: AMSTAR 2 guidance document. *BMJ*, 21(358:j4008), 1–8. Retrieved from
<https://www.bmj.com/content/bmj/suppl/2017/09/21/bmj.j4008.DC1/sheb036104.ww1.pdf>
- Siegenthaler, E., Munder, T., & Egger, M. (2012). Effect of preventive interventions in mentally ill parents on the mental health of the offspring: systematic review and meta-analysis. *Journal of the American Academy of Child & Adolescent Psychiatry*, 51(1), 8–17.
<https://doi.org/10.1016/j.jaac.2011.10.018>
- Silverman, W. K., Ortiz, C. D., Viswesvaran, C., Burns, B. J., Kolko, D. J., Putnam, F. W., & Amaya-Jackson, L. (2008). Evidence-based psychosocial treatments for children and adolescents exposed to traumatic events. *Journal of Clinical Child and Adolescent Psychology*, 37(1), 156–183. <https://doi.org/10.1080/15374410701818293>
- Simsek Arslan, B., Özer, Z., & Buldukoglu, K. (2022). Posttraumatic growth in parentally bereaved children and adolescents: A systematic review. *Death Studies*, 46(1), 111–123.
<https://doi.org/http://dx.doi.org/10.1080/07481187.2020.1716886>
- Slesnick, N., Dashora, P., Letcher, A., Erdem, G., & Serovich, J. (2009). A Review of Services and Interventions for Runaway and Homeless Youth: Moving Forward. *Children & Youth Services Review*, 31(7), 732–742. <https://doi.org/10.1016/j.childyouth.2009.01.006>
- Solomon, D. T., Niec, L. N., & Schoonover, C. E. (2017). The Impact of Foster Parent Training on Parenting Skills and Child Disruptive Behavior: A Meta-Analysis. *Child Maltreatment*, 22(1), 3–13. <https://doi.org/10.1177/1077559516679514>
- Son, G., Jang, J., Hong, E., Park, S., & Choi, K. H. (2024). The Investigation of PTSD in Seoul, South Korea. In Choi, K.H. (Chair), *Disaster and Trauma in South Korea and the Role of Clinical Psychologists*. Symposium conducted at the meeting of Korean Clinical Psychology Association, Changwon, Korea.
- Soneson, E., Das, S., Burn, A. M., van Melle, M., Anderson, J. K., Fazel, M., ... Moore, A. (2023). Leveraging Administrative Data to Better Understand and Address Child Maltreatment: A Scoping Review of Data Linkage Studies. *Child Maltreatment*, 28(1), 176–195.
<https://doi.org/10.1177/10775595221079308>
- Soneson, E., Russo, D., Knight, C., Lafortune, L., Heslin, M., Stochl, J., ... Perez, J. (2019). Psychological

- interventions for people with psychotic experiences: protocol for a systematic review and meta-analysis. *Systematic Reviews*, 8(124), 1–10.
- Stafford, M. R., Jackson, H., Mayo-Wilson, E., Morrison, A. P., & Kendall, T. (2013). Early interventions to prevent psychosis: Systematic review and meta-analysis. *BMJ (Online)*, 346(7892), 1–13. <https://doi.org/10.1136/bmj.f185>
- stem4. (2019). *The Failure of Children and Young People's Mental Health Services: The findings of a major survey of GPs and parents in the UK*. London. Retrieved from <https://stem4.org.uk/wp-content/uploads/2020/01/The-Failure-of-Childrens-Mental-Health-Services-2019-FINAL-31-12-19-1.pdf>
- Stewart, R. E., Chambless, D. L., & Stirman, S. W. (2018). Decision making and the use of evidence based practice: Is the three-legged stool balanced? *Practice Innovations (Washington, D.C.)*, 3(1), 56–67. <https://doi.org/10.1037/pri0000063>
- Stockings, E. A., Degenhardt, L., Dobbins, T., Lee, Y. Y., Erskine, H. E., Whiteford, H. A., & Patton, G. (2016). Preventing depression and anxiety in young people: A review of the joint efficacy of universal, selective and indicated prevention. *Psychological Medicine*, 46(1), 11–26. <https://doi.org/10.1017/S0033291715001725>
- Substance Abuse and Mental Health Services Administration (SAMHSA). (2014). Screening and Assessment. In *A Treatment Improvement Protocol: Trauma-Informed Care in Behavioral Health Services* (pp. 91–110). Rockville, MD: Substance Abuse and Mental Health Services Administration. Retrieved from <https://www.ncbi.nlm.nih.gov/books/NBK207188/>
- Syed, S., Gonzalez-Izquierdo, A., Allister, J., Feder, G., Li, L., & Gilbert, R. (2022). Identifying adverse childhood experiences with electronic health records of linked mothers and children in England: a multistage development and validation study. *The Lancet Digital Health*, 4(7), e482–e496. [https://doi.org/10.1016/s2589-7500\(22\)00061-9](https://doi.org/10.1016/s2589-7500(22)00061-9)
- TED. (2014). Nadine Burke Harris: How childhood trauma affects health across a lifetime [Video file]. Retrieved from https://www.ted.com/talks/nadine_burke_harris_how_childhood_trauma_affects_health_across_a_lifetime?language=en
- Templer, K., Matthewson, M., Haines, J., & Cox, G. (2017). Recommendations for best practice in response to parental alienation: findings from a systematic review. *Journal of Family Therapy*, 39(1), 103–122. <https://doi.org/10.1111/1467-6427.12137>
- Thanhäuser, M., Lemmer, G., de Girolamo, G., & Christiansen, H. (2017). Do preventive interventions for children of mentally ill parents work? Results of a systematic review and meta-analysis. *Current Opinion in Psychiatry*, 30(4), 283–299.

- <https://doi.org/10.1097/YCO.0000000000000342>
- Thapar, A., Eyre, O., Patel, V., & Brent, D. (2022). Depression in young people. *The Lancet*, 400(10352), 617–631. [https://doi.org/10.1016/S0140-6736\(22\)01012-1](https://doi.org/10.1016/S0140-6736(22)01012-1)
- Thayer, D., Rees, A., Kennedy, J., Collins, H., Harris, D., Halcox, J., ... Brooks, C. (2020). Measuring follow-up time in routinely-collected health datasets: Challenges and solutions. *PLOS ONE*, 15(2), e0228545. Retrieved from <https://doi.org/10.1371/journal.pone.0228545>
- The Academy of Medical Sciences. (2024). Prioritising early childhood to promote the nation's health, wellbeing and prosperity, (February). Retrieved from <https://acmedsci.ac.uk/more/news/urgent-action-needed-on-failing-child-health?>
- The Child Safeguarding Practice Review Panel. (2022). *Child Protection in England: National review into the murders of Arthur Labinjo-Hughes and Star Hobson*. Retrieved from www.nationalarchives.gov.uk/doc/open-government-licence/version/3
- The Health Foundation. (2024). Relationship between persistent poverty and health. Retrieved August 18, 2024, from <https://www.health.org.uk/evidence-hub/money-and-resources/persistent-poverty/relationship-between-persistent-poverty-and-health>
- The Philadelphia ACE Project. (2019). Philadelphia ACE Survey: What are Adverse Childhood Experiences (ACES)? Retrieved from <https://www.philadelphiaaces.org/philadelphia-ace-survey>
- Thomas, J., Graziosi, S., Brunton, J., Ghouze, Z., O'Driscoll, P., Bond, M., & Koryakina, A. (2023). EPPI-Reviewer: advanced software for systematic reviews, maps and evidence synthesis. EPPI-Centre, UCL Social Research Institute, University College London.
- Thomson, K., Bambra, C., McNamara, C., Huijts, T., & Todd, A. (2016). The effects of public health policies on population health and health inequalities in European welfare states: Protocol for an umbrella review. *Systematic Reviews*, 5(1). <https://doi.org/10.1186/s13643-016-0235-3>
- Tibble, H., Law, H. Di, Spittal, M. J., Karmel, R., Borschmann, R., Hail-Jares, K., ... Kinner, S. A. (2018). The importance of including aliases in data linkage with vulnerable populations. *BMC Medical Research Methodology*, 18(1), 1–5. <https://doi.org/10.1186/s12874-018-0536-4>
- Tony Blair Institute for Global Change. (2024). Reimagining Health Care – with Dr John-Arne Røttingen, Professor Andrew Scott and Tony Blair, moderated by Dr Charlotte Refsum. In *Future of Britain 2024*. Retrieved from <https://www.institute.global/future-of-britain-conference-2024#opening-session-2024>
- Tourangeau, R., & Yan, T. (2007). Sensitive questions in surveys. *Psychological Bulletin*, 133(5), 859–883. <https://doi.org/10.1037/0033-2909.133.5.859>
- Treanor, M. (2018). Poverty and Adverse Childhood Experiences (ACEs). Retrieved July 2, 2024, from <https://www.children1st.org.uk/about-us/news/blog/poverty-and-adverse-childhood->

experiences-aces/#:~:text=Poverty is not another ACE&text=Often poverty is described as,by political and economic factors.

- Troy, V., McPherson, K. E., Emslie, C., & Gilchrist, E. (2018). The Feasibility, Appropriateness, Meaningfulness, and Effectiveness of Parenting and Family Support Programs Delivered in the Criminal Justice System: A Systematic Review. *Journal of Child and Family Studies*, 27(6), 1732–1747. <https://doi.org/10.1007/s10826-018-1034-3>
- Turner, W., Macdonald, G., & Dennis, J. A. (2007). Behavioural and cognitive behavioural training interventions for assisting foster carers in the management of difficult behaviour (Review). *Cochrane Database of Systematic Reviews*, (1), 1–50. <https://doi.org/10.1002/14651858.CD003760.pub3>
- UK Clinical Research Collaboration (UKCRC). (2007). *UKCRC R&D Advisory Group to Connecting for Health: Report of Research Simulations*. Retrieved from <https://www.ukcrc.org/wp-content/uploads/2014/06/CfH-report-June-07-full.pdf>
- UK Clinical Research Collaboration (UKCRC). (2008). *UK Clinical Research Collaboration Progress Report 2006 - 2008*. Retrieved from https://ukcrc-org.stackstaging.com/wp-content/uploads/2014/03/UKCRC_Progress_2006-2008.pdf
- UK National Screening Committee. (2015). Guidance: Criteria for appraising the viability, effectiveness and appropriateness of a screening programme. Retrieved from <https://www.gov.uk/government/publications/evidence-review-criteria-national-screening-programmes/criteria-for-appraising-the-viability-effectiveness-and-appropriateness-of-a-screening-programme>
- Uretsky, M. C., & Hoffman, J. A. (2017). Evidence for Group-Based Foster Parent Training Programs in Reducing Externalizing Child Behaviors: A Systematic Review and Meta-Analysis. *Journal of Public Child Welfare*, 11(4–5), 464–486. <https://doi.org/10.1080/15548732.2017.1326360>
- Van Andel, H. W. H., Grietens, H., Strijker, J., Van der Gaag, R. J., & Knorth, E. J. (2014). Searching for effective interventions for foster children under stress: a meta-analysis. *Child & Family Social Work*, 19(2), 149–155. <https://doi.org/10.1111/j.1365-2206.2012.00885.x>
- Van Niel, C., Pachter, L. M., Wade, R. J., Felitti, V. J., & Stein, M. T. (2014). Adverse Events in Children: Predictors of Adult Physical and Mental Conditions. *Journal of Developmental & Behavioral Pediatrics*, 35(8). Retrieved from https://journals.lww.com/jrnldb/Fulltext/2014/10000/Adverse_Events_in_Children__Predictors_of_Adult.9.aspx
- Vederhus, J.-K., Haugland, S. H., & Timko, C. (2022). A mediational analysis of adverse experiences in childhood and quality of life in adulthood. *International Journal of Methods in Psychiatric*

- Research*, 31(1), e1904. <https://doi.org/10.1002/mpr.1904>
- Verheij, R. A., Curcin, V., Delaney, B. C., & McGilchrist, M. M. (2018). Possible sources of bias in primary care electronic health record data use and reuse. *Journal of Medical Internet Research*, 20(5). <https://doi.org/10.2196/JMIR.9134>
- Vink, R. M., van Dommelen, P., van der Pal, S. M., Eekhout, I., Pannebakker, F. D., Klein Velderman, M., ... Dekker, M. (2019). Self-reported adverse childhood experiences and quality of life among children in the two last grades of Dutch elementary education. *Child Abuse and Neglect*, 95(January), 104051. <https://doi.org/10.1016/j.chiabu.2019.104051>
- Waechter, R. L., & Wekerle, C. (2015). Promoting Resilience Among Maltreated Youth Using Meditation, Yoga, Tai Chi and Qigong: A Scoping Review of the Literature. *Child & Adolescent Social Work Journal*, 32, 17–31. <https://doi.org/10.1007/s10560-014-0356-2>
- Wampold, B. E. (2015). How important are the common factors in psychotherapy? An update. *World Psychiatry : Official Journal of the World Psychiatric Association (WPA)*, 14(3), 270–277. <https://doi.org/10.1002/wps.20238>
- Warrier, U., Warrier, A., & Khandelwal, K. (2023). Ethical considerations in the use of artificial intelligence in mental health. *Egyptian Journal of Neurology, Psychiatry and Neurosurgery*, 59(1). <https://doi.org/10.1186/s41983-023-00735-2>
- Weetman, C., Kiemle, G., Lowe, M., & Balfour, R. (2022). The Experience of Partner Relationships for Male Survivors of Childhood Sexual Abuse: A Qualitative Synthesis. *Trauma, Violence & Abuse*, 23(5), 1478–1493. <https://doi.org/http://dx.doi.org/10.1177/1524838021998311>
- Welsh Government. (2012). *Together for Mental health: A Strategy for Mental Health and Wellbeing in Wales*. Welsh Government. Retrieved from <https://gov.wales/docs/dhss/publications/121031tmhfinalen.pdf%0Ahttp://wales.gov.uk/docs/dhss/publications/121031tmhfinalen.pdf>
- Welsh Government. (2024). Data collection: Local authority social services. Retrieved May 22, 2024, from <https://www.gov.wales/sites/default/files/statistics-and-research/2023-04/children-receiving-care-and-support-census-2022-23-notes.pdf>
- What Works Wellbeing. (2017). *Briefing: unemployment, (re)employment and wellbeing*. Retrieved from www.whatworkswellbeing.org
- White, P., George, A., & Bourne, T. (2016). Linked data for quality monitoring and commissioning for health and care service planning. *European Journal of Epidemiology*, 31 (Supple, S228–S229. Retrieved from <https://ovidsp.ovid.com/athens/ovidweb.cgi?T=JS&CSC=Y&NEWS=N&PAGE=fulltext&D=emed17&AN=612039215https://cambridge->

- primo.hosted.exlibrisgroup.com/openurl/44CAM/44CAM_services_page?sid=OVID:embase&id=pmid:&id=doi:10.1007%2Fs10654-016-0183-1&issn=1573-7284&i
- Whitley, R., Kirmayer, L. J., & Groleau, D. (2006). Understanding immigrants' reluctance to use mental health services: a qualitative study from Montreal. *The Canadian Journal of Psychiatry*, 51(4), 205–209.
- Wickersham, A., & Downs, J. (2022). Clinical applications of big data to child and adolescent mental health care. In M. Hodes & P. De Vries (Eds.), *Shaping the Future of Child and Adolescent Mental Health* (1st ed., pp. 59–79). Elsevier. Retrieved from <https://www.elsevier.com/books/shaping-the-future-of-child-and-adolescent-mental-health/hodes/978-0-323-91709-4>
- Wickham, H. (2016). *ggplot2: Elegant Graphics for Data Analysis*. Springer-Verlag New York. <https://doi.org/ISBN: 978-3-319-24277-4>
- Williamson, K., Landis, D., Shannon, H., Gupta, P., & Gillespie, L.-A. (2017). *The Impact of Protection Interventions on Unaccompanied and Separated Children in Humanitarian Crises*. Humanitarian Evidence Programme. Oxford: Oxfam GB. Retrieved from <https://oxfamilibrary.openrepository.com/bitstream/10546/620204/1/rr-protection-intervention-impact-children-030317-en.pdf>
- Wilson, B., & Barnett, L. M. (2020). Physical activity interventions to improve the health of children and adolescents in out of home care — A systematic review of the literature. *Children and Youth Services Review*, 110, 1–20. <https://doi.org/10.1016/j.childyouth.2020.104765>
- Winokur, M. A., Holtan, A., & Batchelder, K. E. (2014). Kinship Care for the Safety, Permanency, and Well-being of Children Removed from the Home for Maltreatment: A Systematic Review. *Campbell Systematic Reviews*, 10(1), 1–292. <https://doi.org/10.4073/csr.2014.2>
- Winokur, M. A., Holtan, A., & Batchelder, K. E. (2018). Systematic Review of Kinship Care Effects on Safety, Permanency, and Well-Being Outcomes. *Research on Social Work Practice*, 28(1), 19–32. <https://doi.org/10.1177/1049731515620843>
- Wiseman, H., Hamilton-Giachritsis, C., & Hiller, R. M. (2021). The Relevance of Cognitive Behavioral Models of Post-Traumatic Stress Following Child Maltreatment: A Systematic Review. *Trauma, Violence & Abuse*, 22(1), 191–206. <https://doi.org/http://dx.doi.org/10.1177/1524838019827894>
- Wolpert, M., Harris, R., Hodges, S., Fuggle, P., James, R., Wiener, A., ... Munk, S. (2016). *THRIVE Elaborated* (2nd ed.). London, UK: CAMHS Press. Retrieved from <https://discovery.ucl.ac.uk/id/eprint/10126128/1/thrive-elaborated-2nd-edition.pdf>
- Wood, S., Ford, K., Hardcastle, K., Hopkins, J., Hughes, K., & Bellis, M. A. (2020). Adverse Childhood

- Experiences in child refugee and asylum seeking populations. *Public Health Wales NHS Trust*.
- Woodman, J., Freemantle, N., Allister, J., de Lusignan, S., Gilbert, R., & Petersen, I. (2012). Variation in recorded child maltreatment concerns in UK primary care records: a cohort study using The Health Improvement Network (THIN) database. *PLoS One*, 7(11), e49808.
- World Health Organization. (2014). Adverse childhood experiences international questionnaire (ACE-IQ) guidance for analysing ACE-IQ. Retrieved from https://cdn.who.int/media/docs/default-source/documents/child-maltreatment/ace-questionnaire.pdf?sfvrsn=baed215c_2
- World Health Organization. (2021). *Ethics and Governance of Artificial Intelligence for Health: WHO guidance*. Geneva: World Health Organization. https://doi.org/10.1142/9789811238819_0001
- World Health Organization. (2024). Social determinants of health. Retrieved May 15, 2024, from https://www.who.int/health-topics/social-determinants-of-health#tab=tab_1
- Wykes, T., Bell, A., Carr, S., Coldham, T., Gilbody, S., Hotopf, M., ... Creswell, C. (2021). Shared goals for mental health research: what, why and when for the 2020s. *Journal of Mental Health*, 1–9. <https://doi.org/10.1080/09638237.2021.1898552>
- Xu, Y., & Bright, C. L. (2018). Children's mental health and its predictors in kinship and non-kinship foster care: A systematic review. *Children and Youth Services Review*, 89, 243–262. <https://doi.org/10.1016/j.childyouth.2018.05.001>
- YoungMinds. (n.d.). *A new era for young people's mental health*. London. Retrieved from <https://www.youngminds.org.uk/media/5dilibjw/a-new-era-for-young-peoples-mental-health.pdf>
- Ziviani, J., Feeney, R., Cuskelly, M., Meredith, P., & Hunt, K. (2012). Effectiveness of support services for children and young people with challenging behaviours related to or secondary to disability, who are in out-of-home care: A systematic review. *Children and Youth Services Review*, 34(4), 758–770. <https://doi.org/10.1016/j.childyouth.2012.01.002>

9 Appendices

9.1 Appendix A – Chapter 4: A Delphi Study of Risk Factors for Mental Health Problems

9.1.1 Appendix A.1 – Ranked risk factors within domains 1-8

Table 45: Ranked importance of risk factors within domain 1: Social and Environmental

Tied position	Rank within domain (out of 106)	Risk factor	Number of raters (N)	Mean score	Lower bound (CI)	Upper bound (CI)
	1	Being a looked after child (LAC)	14	0.014	0.010	0.025
	2	Torture	13	0.014	0.003	0.024
	3	Sexual abuse	16	0.014	0.012	0.023
	4	Lack of supportive relationship(s) with a trusted adult	15	0.014	0.011	0.024
=	5	Poor primary caregiver-caregiver relationship	16	0.013	0.008	0.020
=	5	Cumulative traumatic events	16	0.013	0.012	0.025
=	7	Domestic violence	16	0.013	0.011	0.023
=	7	Trauma severity	14	0.013	0.009	0.023
	9	Emotional, psychological or verbal abuse	16	0.013	0.012	0.024
	10	Emotional neglect	16	0.013	0.011	0.025
	11	Victim of organised crime (e.g. commercial sexual exploitation or via county lines)	13	0.013	0.011	0.022
=	12	Household drug abuse	16	0.013	0.010	0.021
=	12	Poor primary caregiver-child relationship	16	0.013	0.010	0.024
	14	Physical abuse	16	0.013	0.008	0.020
	15	Household mental illness	16	0.013	0.010	0.020
	16	Family conflict or discord	16	0.013	0.009	0.023
	17	Death of primary caregiver(s)	16	0.013	0.009	0.020
	18	Caregiver negative attitude to mental health problems	16	0.012	0.008	0.022
	19	Separation from family (e.g. out-of-home care)	15	0.012	0.011	0.022
=	20	Homelessness	16	0.012	0.008	0.023

=	20	Chronic psychological stress	16	0.012	0.004	0.021
	22	Household alcohol abuse	16	0.012	0.009	0.021
	23	Family experience of social exclusion, discrimination and harassment associated with ethnicity	14	0.012	0.008	0.022
	24	Victim or witness of violent crime	13	0.012	0.009	0.018
	25	Social isolation	16	0.012	0.009	0.021
	26	Physical neglect	16	0.012	0.003	0.021
	27	Witnessing injury/death during a traumatic event	14	0.012	0.009	0.016
	28	Being an unaccompanied asylum seeker	15	0.012	0.005	0.021
=	29	Being an asylum-seeking family	14	0.012	0.008	0.017
=	29	Victim of bullying	16	0.012	0.009	0.015
=	31	Experience of racism and discrimination	15	0.012	0.007	0.017
=	31	Child in need (CIN) status	15	0.012	0.003	0.021
	33	Maternal substance abuse during pregnancy	14	0.012	0.005	0.019
	34	Imprisonment	14	0.012	0.009	0.021
	35	Experience of past traumatic event	16	0.012	0.010	0.014
	36	Frequent fear of family member	16	0.012	0.004	0.022
=	37	Involvement in criminal justice system	15	0.012	0.009	0.015
=	37	Homelessness (young person has left home)	15	0.012	0.009	0.018
	39	War/conflict	13	0.012	0.007	0.026
	40	Victim of structural/systemic racism	13	0.012	0.002	0.017
	41	Witness of community violence	13	0.012	0.008	0.016
	42	Household criminality	16	0.012	0.006	0.017
	43	Area deprivation (area code)	15	0.011	0.007	0.025
	44	Injury during a traumatic event	14	0.011	0.005	0.014
	45	Household member involvement in criminal justice system	16	0.011	0.006	0.018
	46	Disabled child/young person experiencing infantilisation	10	0.011	0.008	0.014
	47	Maternal lead exposure during pregnancy	8	0.011	0.004	0.013
	48	Maternal use of psychotropics during pregnancy	11	0.011	0.002	0.019
	49	Imprisonment of household member	14	0.011	0.002	0.015
	50	Maternal alcohol use during pregnancy	15	0.011	0.005	0.019

51	Poor peer relationships	16	0.011	0.008	0.019
52	Cultural racism	14	0.011	0.005	0.026
53	Organised crime affiliation	12	0.011	0.007	0.013
54	Death of a close friend	16	0.011	0.007	0.016
55	Trapped during earthquake	11	0.011	0.002	0.012
56	Family has low trust in services	15	0.011	0.003	0.022
57	Famine	12	0.011	0.003	0.017
58	Family financial problems	15	0.011	0.007	0.014
59	Low social support for family	16	0.011	0.008	0.015
60	Being an adoptee	15	0.011	0.003	0.021
61	Gangland crime	13	0.011	0.003	0.016
62	Being a young carer	16	0.011	0.006	0.019
63	Frequently moving homes	15	0.010	0.003	0.015
= 64	Ethnic minority in low ethnic density area	13	0.010	0.004	0.019
= 64	Experiencing financial abuse	13	0.010	0.004	0.014
66	Personal direct experience of natural disaster	16	0.010	0.003	0.013
67	Household overcrowding	14	0.010	0.003	0.014
68	Perceived pressure to be thin	16	0.010	0.002	0.015
69	Poverty	16	0.010	0.002	0.016
70	Minority gender identity	11	0.010	0.003	0.014
71	Food poverty	13	0.010	0.004	0.013
72	Poor online peer relationships	16	0.010	0.005	0.015
73	Minority sexuality	12	0.010	0.003	0.014
74	Death of close relative (excluding primary caregiver(s))	16	0.010	0.002	0.015
75	Being a young parent	16	0.010	0.004	0.014
76	Radicalisation	12	0.010	0.001	0.019
77	English as an additional language	13	0.010	0.002	0.016
78	Racial bias in obstetric care	11	0.009	0.001	0.018
79	Maternal smoking during pregnancy	12	0.009	0.001	0.013
80	Low socioeconomic status family	16	0.009	0.002	0.014

81	Primary caregiver(s) parenting styles (strict/rigid/conventional)	16	0.009	0.002	0.018
82	Living in an area with high crime levels	13	0.009	0.001	0.013
83	Migration from another country	14	0.009	0.002	0.011
84	Remoteness of living	12	0.009	0.001	0.022
85	Belonging to a traveller community	14	0.009	0.002	0.012
86	Negative previous experiences of services	16	0.009	0.005	0.016
87	Belonging to a religious minority	14	0.008	0.001	0.013
88	Air pollution	12	0.007	0.000	0.013
89	Blended or complex family structure	16	0.007	0.003	0.019
90	Primary caregiver(s) unemployment	16	0.007	0.001	0.009
91	Digital exclusion	11	0.007	0.004	0.012
92	Being a second generation immigrant	13	0.006	0.000	0.009
93	Number of living children in the family	15	0.006	0.000	0.013
94	Urbanicity	12	0.006	0.000	0.011
95	Climate change	11	0.006	0.003	0.009
96	Ethnicity	11	0.006	0.003	0.011
97	Smoking status of primary caregiver(s)	13	0.006	0.001	0.011
98	Multi-generational families within the same home	13	0.005	0.000	0.008
99	Religiosity of caregiver(s)	13	0.005	0.000	0.007
100	Child younger than classmates	13	0.005	0.000	0.009
101	Single parent/caregiver family	16	0.005	0.000	0.011
102	Religiosity	12	0.004	0.000	0.009
103	Not breast fed	10	0.003	0.000	0.010
104	Month of birth	12	0.003	0.000	0.006
105	High socioeconomic status family	15	0.003	0.000	0.007
106	Primary caregiver(s) marital status	16	0.003	0.000	0.009

Range: 8 - 16

Headers: CI = confidence intervals

Table 46: Ranked importance of risk factors within domain 2: Behavioural

Tied position	Rank within domain (out of 23)	Risk factor	Number of raters (N)	Mean score	Lower bound (CI)	Upper bound (CI)
	1	Heavy alcohol use	14	0.085	0.047	0.187
	2	Poor sleep patterns	14	0.079	0.049	0.135
	3	Sexual risk-taking	14	0.074	0.043	0.114
	4	Prescription drug abuse	11	0.069	0.025	0.173
	5	Higher behavioural inhibition	10	0.059	0.036	0.112
	6	Non-prescription drug use	12	0.056	0.026	0.135
	7	Frequent social media use	14	0.053	0.029	0.083
	8	Physical inactivity	13	0.051	0.017	0.075
	9	Unhealthy diet in family/primary caregiver(s)	14	0.049	0.021	0.091
	10	Smoking	13	0.049	0.008	0.083
	11	Physical inactivity in family/primary caregiver(s)	14	0.048	0.015	0.097
	12	Nitrous oxide use	8	0.047	0.030	0.063
	13	High levels of ultra-processed foods in diet	8	0.045	0.028	0.073
	14	Unhealthy diet	13	0.044	0.009	0.073
	15	Lower behavioural inhibition	10	0.044	0.024	0.147
	16	Foods high in trans fats in diet	10	0.040	0.007	0.077
	17	Excessive sports participation	12	0.039	0.016	0.072
	18	Low sports participation	12	0.039	0.006	0.064
	19	Diet low in plant-matter diversity	8	0.039	0.003	0.057
	20	Excessive physical activity	12	0.038	0.016	0.133
	21	High ratio of omega-6 to omega-3 fatty acids in diet	6	0.037	0.020	0.047
	22	Low levels of omega-3 polyunsaturated fatty acids in diet	6	0.036	0.019	0.048
	23	Diet low in plant-matter	9	0.034	0.008	0.055
			Range: 6 - 14			

Headers: CI = confidence intervals

Table 47: Ranked importance of risk factors within domain 3: Education and Employment

Tied position	Rank within domain (out of 25)	Risk factor	Number of raters (N)	Mean score	Lower bound (CI)	Upper bound (CI)
	1	School exclusions	7	0.056	0.049	0.105
	2	Quality of school climate (e.g. relating to school connectedness, feelings of safety in school, perception of school, adult-student relationships, morale)	6	0.053	0.037	0.074
=	3	Disruptive behaviours in school (e.g. defiance and non-compliance)	7	0.052	0.040	0.093
=	3	Poor peer relationships	7	0.052	0.039	0.088
=	3	Poor school attendance	7	0.052	0.039	0.089
=	3	Poor teacher-pupil relationship	7	0.052	0.041	0.063
	7	Having an Education and Health Care Plan (EHCP)	7	0.050	0.031	0.083
	8	Out-of-school discipline (e.g. suspension and expulsion)	6	0.050	0.039	0.099
	9	Poor school climate (e.g. Ofsted weightings)	6	0.049	0.031	0.063
	10	Special Educational Needs (SEN)	7	0.049	0.032	0.085
	11	Poor quality or a lack of social-emotional learning programmes in pre-school	7	0.047	0.014	0.061
=	12	Home schooling (not by choice)	7	0.046	0.032	0.083
=	12	Negative experience of home schooling	7	0.046	0.026	0.099
	14	Increased pressure/stress for teachers (e.g. insufficient pay/resources and poor leadership)	6	0.042	0.007	0.072
	15	Language impairment in primary caregiver(s)	7	0.039	0.013	0.072
	16	Poor educational attainment	7	0.037	0.016	0.076
	17	Unemployment of the individual	6	0.035	0.011	0.052
	18	Lack of imitation games with caregivers by age 1	5	0.032	0.016	0.050
	19	Serving in the military	3	0.030	0.019	0.031
	20	Low education level of primary caregiver(s)	7	0.029	0.012	0.057
	21	Child not read to daily by age 1	6	0.029	0.004	0.044
	22	School-level deprivation (e.g. proportion eligible for free school meals)	6	0.020	0.008	0.058
	23	Participation in the Free-Lunch Program	6	0.019	0.011	0.031
	24	School composition (e.g. size/headcount, gender proportions, ethnicity proportions)	5	0.019	0.010	0.038
	25	Low education level of caregiver(s) (other than primary caregiver(s))	6	0.018	0.003	0.039
Range: 3 - 7						

Headers: CI = confidence intervals

Table 48: Ranked importance of risk factors within domain 4: Biomarkers

Tied position	Rank within domain (out of 48)	Risk factor	Number of raters (N)	Mean score	Lower bound (CI)	Upper bound (CI)
	1	Low intelligence quotient (IQ)	3	0.077	0.052	0.171
	2	Genetic markers	3	0.057	0.027	0.108
	3	Sex (biological)	3	0.048	0.036	0.081
	4	Nutritional deficits	2	0.044	0.037	0.051
	5	Neurotoxicity	3	0.044	0.043	0.123
	6	Neuronal atrophy	2	0.043	0.043	0.043
	7	Increased neurodegeneration	3	0.042	0.038	0.147
	8	Reduced neuroplasticity	2	0.042	0.041	0.042
	9	Low levels of dopamine	2	0.041	0.037	0.046
	10	Low levels of nutrients	2	0.041	0.034	0.048
	11	Low levels of serotonin	2	0.041	0.037	0.045
	12	Reduced neurogenesis	2	0.041	0.039	0.042
	13	HPA axis and glucocorticoid receptor resistance	1	0.039	0.039	0.039
	14	Low levels of folate	1	0.037	0.037	0.037
	15	Reduced levels of BDNF (i.e. neurotrophic factor)	1	0.036	0.036	0.036
	16	Reduced grey matter in hippocampus	2	0.036	0.030	0.042
	17	Raised levels of glucocorticoids/cortisol	2	0.035	0.030	0.039
	18	High levels of cytokine proteins (e.g. interleukin-1 [IL-1]; interleukin-6 [IL-6])	1	0.035	0.035	0.035
	19	Birth weight	3	0.034	0.022	0.109
	20	Raised C-reactive protein (CRP)	2	0.033	0.029	0.037
	21	Low levels of vitamin D	2	0.032	0.028	0.037
	22	Decreased neuronal branching	2	0.032	0.025	0.039
	23	Low levels of melatonin	1	0.031	0.031	0.031
	24	Low serum ferritin	2	0.031	0.028	0.034
	25	Changes in prefrontal cortex (e.g. reduced total volume; low myelination; low white matter; increased middle inferior and ventral regions and superior/dorsal regions)	2	0.029	0.013	0.045
=	26	Age of parents at time of giving birth	3	0.028	0.007	0.087
=	26	High intelligence quotient (IQ)	3	0.028	0.001	0.142

=	28	Epigenetic marker - DNA methylation	1	0.026	0.026	0.026
=	28	Epigenetic marker - non-coding ribonucleic acids	1	0.026	0.026	0.026
	28	Gut microbiome (reduced diversity and reduced populations of certain bacteria)	1	0.026	0.026	0.026
	31	Epigenetic marker - chromatin regulation	1	0.025	0.025	0.025
	32	Chronic inflammation	1	0.024	0.024	0.024
	33	Changes in amygdala (e.g. reduced volume)	2	0.024	0.017	0.031
	34	Birth length	2	0.014	0.005	0.022

Range: 1 - 3

Headers: **CI** = confidence intervals

Table 49: Ranked importance of risk factors within domain 5: Physical Health

Tied position	Rank within domain (out of 52)	Risk factor	Number of raters (N)	Mean score	Lower bound (CI)	Upper bound (CI)
	1	Traumatic brain injury	6	0.047	0.022	0.092
	2	Primary caregiver(s) chronic (long lasting) illness	6	0.043	0.022	0.086
	3	Severe health condition	6	0.042	0.023	0.068
	4	Severe illness in family	6	0.040	0.022	0.092
	5	Sleep disorder	6	0.037	0.023	0.091
	6	Physical disability	6	0.036	0.017	0.043
	7	Global developmental delay	6	0.034	0.020	0.045
	8	Prolonged duration of a physical health condition	5	0.034	0.014	0.065
	9	Irritable Bowel Syndrome (IBS)	5	0.033	0.017	0.070
	10	Lack of response to treatment for a physical health condition	4	0.030	0.020	0.042
	11	Diabetes	6	0.028	0.010	0.041
	12	Hearing impairment causing disability (e.g. deafness)	6	0.028	0.021	0.046
	13	Autoimmune disorders (e.g. rheumatoid arthritis)	6	0.027	0.014	0.034
	14	Hypoxia (at birth)	4	0.027	0.006	0.047
	15	Maternal obesity/overweight during pregnancy	2	0.026	0.020	0.032
	16	Visual impairment causing disability (e.g. blindness/partial sightedness)	5	0.025	0.017	0.073
	17	Thyroid disease	5	0.024	0.015	0.043
	18	Congenital malformations	5	0.023	0.011	0.046
	19	5-min Apgar score <7	6	0.022	0.001	0.034
	20	Asthma	6	0.022	0.012	0.040
	21	Anaemia	6	0.021	0.016	0.024
	22	Premature birth	6	0.021	0.003	0.041
=	23	Low diversity and composition of gut microbiota	3	0.021	0.021	0.038
=	23	Repeated infections	5	0.021	0.012	0.029
	25	Pre-eclampsia	4	0.021	0.002	0.021
	26	Inflammatory diseases (e.g. Lyme disease)	5	0.021	0.014	0.033
=	27	Maternal hypertension during pregnancy	1	0.021	0.021	0.021

= 27	Maternal infection requiring hospitalisation during pregnancy	1	0.021	0.021	0.021
= 27	Maternal diabetes during pregnancy	1	0.021	0.021	0.021
= 27	Chronic (long lasting) infection (e.g. Lyme disease, periodontal disease)	5	0.021	0.006	0.034
= 31	Low serum vitamin D	5	0.021	0.001	0.025
= 31	Maternal auto-immune disease during pregnancy	1	0.021	0.021	0.021
33	Perinatal infections (e.g. cytomegalovirus)	6	0.020	0.002	0.039
34	Family history of autoimmune disease	6	0.020	0.000	0.023
35	Chronic (long lasting) gastric ill-health (e.g. inflammatory bowel disease)	5	0.020	0.009	0.039
36	Obstetric complications (other)	4	0.019	0.001	0.032
37	Disease history	3	0.018	0.011	0.027
38	Dental caries (tooth decay)	6	0.017	0.003	0.030
39	Chronic (long lasting) reflux or indigestion	5	0.017	0.001	0.033
40	Allergies (e.g. non-IgE-mediated food allergies, pollen allergies)	6	0.017	0.000	0.021
41	Family history of psoriasis	4	0.016	0.011	0.023
42	Obesity/overweight	4	0.016	0.011	0.023
43	Body Mass Index (BMI)	5	0.016	0.009	0.055
44	Eczema	6	0.015	0.001	0.033
45	Long term antibiotic use	4	0.015	0.008	0.039
46	Family history of Type 1 diabetes	6	0.014	0.000	0.021
47	Family history of rheumatoid arthritis	4	0.013	0.001	0.023
48	Maternal self-rated health (prior to pregnancy)	4	0.013	0.000	0.036
49	Dental erosion	4	0.009	0.000	0.030
50	Polyhydramnios	3	0.005	0.000	0.020
51	Ruptured membranes (at birth)	4	0.003	0.000	0.018

Range: 1 - 6

Headers: CI = confidence intervals

Table 50: Ranked importance of risk factors within domain 6: Psychological and Mental Health

Tied position	Rank within domain (out of 26)	Risk factor	Number of raters (N)	Mean score	Lower bound (CI)	Upper bound (CI)
	1	Family history of severe mental illness (e.g. psychosis)	14	0.050	0.034	0.071
	2	Primary caregiver(s) mental health problems	14	0.046	0.038	0.072
	3	Psychiatric history	14	0.045	0.037	0.075
	4	Family history of psychiatric disorders	14	0.043	0.034	0.074
	5	Social-communication problems	14	0.043	0.030	0.063
	6	Neuro-developmental conditions (e.g. autism)	13	0.042	0.036	0.069
	7	Increased panic attacks	13	0.042	0.032	0.061
	8	Anxiety (as a predictor of further mental health problems)	14	0.040	0.031	0.069
=	9	High levels of perceived stress	13	0.040	0.034	0.067
=	9	Ineffective coping strategies	13	0.040	0.027	0.057
	11	Maternal psychosis (perinatal or pre-natal)	12	0.040	0.023	0.054
	12	Lack of psychological resilience	14	0.040	0.026	0.067
	13	Attention (as a predictor of further mental health problems)	13	0.040	0.027	0.061
	14	Intellectual disability	12	0.040	0.022	0.052
	15	Increased anxiety arousal	13	0.039	0.010	0.046
	16	Dissociation during traumatic experience	12	0.039	0.026	0.051
	17	Acute stress symptoms (anxiety, avoidance or depression - as a predictor of further mental health problems)	14	0.039	0.014	0.069
	18	Acute stress disorder (as a predictor of further mental health problems)	14	0.039	0.020	0.066
	19	Excessive rumination	13	0.039	0.022	0.049
	20	Poor concentration	13	0.039	0.018	0.046
	21	Negative attitudes to mental health problems within society an individual lives in	14	0.038	0.000	0.070
	22	Maternal depression during pregnancy	12	0.038	0.012	0.044
	23	Poor problem-solving abilities	13	0.037	0.017	0.048
	24	Emotional reactivity	14	0.036	0.007	0.062
	25	Poor visuospatial functioning	10	0.036	0.012	0.042
	26	Problems with memory	13	0.035	0.019	0.045
Range: 10 - 14						

Headers: CI = confidence intervals

Table 51: Ranked importance of risk factors within domain 7: Patterns of Service Use

Tied position	Rank within domain (out of 7)	Risk factor	Number of raters (N)	Mean score	Lower bound (CI)	Upper bound (CI)
	1	Child protection record	6	0.203	0.158	0.273
	2	Investigations by multiple services suggestive of suffering from medically unexplained symptoms	7	0.186	0.149	0.248
	3	Failure to attend three or more planned health or social care appointments	7	0.168	0.115	0.230
	4	Three or more presentations to emergency services within a year	6	0.158	0.085	0.387
	5	Repeat hospitalisation	6	0.144	0.109	0.288
	6	Missed ante-natal visits	6	0.120	0.024	0.247
	7	Primary caregiver(s) non-attendance at baby groups	7	0.023	0.000	0.104
Range: 6 - 7						

Headers: CI = confidence intervals

Table 52: Ranked importance of risk factors within domain 8: Factors Identified to be Particularly Relevant to Under-Served Populations

Tied position	Rank within domain (out of 102)	Risk factor	Number of raters (N)	Mean score	Lower bound (CI)	Upper bound (CI)
	1	Being a looked after child (LAC)	5	0.016	0.011	0.029
	2	Child in need (CIN) status	5	0.016	0.011	0.021
	3	Torture	5	0.015	0.012	0.019
	4	Separation from family (e.g. out-of-home care)	6	0.015	0.012	0.027
	5	Child protection record	6	0.015	0.012	0.022
	6	Heavy alcohol use	6	0.014	0.012	0.023
	7	Victim of organised crime (e.g. commercial sexual exploitation or via county lines)	5	0.014	0.012	0.021
	8	Imprisonment	5	0.014	0.012	0.029
	9	Homelessness (young person has left home)	6	0.014	0.012	0.025
	10	Primary caregiver(s) mental health problems	6	0.014	0.011	0.028
	11	Victim or witness of violent crime	6	0.013	0.007	0.016
	12	Experience of bereavement during a traumatic event ^Ψ	6	0.013	0.010	0.018
	13	Victim of structural/systemic racism	6	0.013	0.003	0.017
	14	Being an asylum-seeking family	6	0.013	0.009	0.018
	15	Homelessness	6	0.013	0.011	0.018
	16	Household mental illness	6	0.013	0.012	0.023
	17	War/conflict	6	0.013	0.011	0.016
=	18	Gangland crime	6	0.013	0.004	0.016
=	18	Family experience of social exclusion, discrimination and harassment associated with ethnicity	6	0.013	0.003	0.017
	20	Witnessing injury/death during a traumatic event	6	0.013	0.011	0.016
	21	Neuro-developmental conditions (e.g. autism)	6	0.013	0.008	0.017
	22	Experience of racism and discrimination	6	0.013	0.009	0.020
	23	Disabled child/young person experiencing infantilisation	2	0.013	0.012	0.013
	24	Out-of-school discipline (e.g. suspension and expulsion)	6	0.013	0.012	0.024
	25	Being an unaccompanied asylum seeker	6	0.012	0.012	0.021
	26	Famine	5	0.012	0.004	0.016
=	27	Household drug abuse	6	0.012	0.011	0.016

=	27	Household member involvement in criminal justice system	6	0.012	0.012	0.013
	29	Being a young carer	6	0.012	0.005	0.017
	30	Radicalisation	6	0.012	0.002	0.016
	31	Organised crime affiliation	5	0.012	0.010	0.013
	32	Household alcohol abuse	6	0.012	0.010	0.016
	33	Involvement in criminal justice system	6	0.012	0.011	0.027
	34	Witness of community violence	6	0.012	0.007	0.013
	35	School exclusions	6	0.012	0.008	0.024
	36	Family has low trust in services	6	0.012	0.009	0.017
	37	Household criminality	6	0.012	0.011	0.015
	38	Imprisonment of household member	5	0.012	0.006	0.012
	39	Non-prescription drug use	6	0.012	0.009	0.014
	40	Poor school attendance	6	0.012	0.009	0.026
	41	Maternal substance abuse during pregnancy	6	0.012	0.005	0.015
	42	Poor school climate (e.g. Ofsted weightings)	6	0.011	0.009	0.015
	43	Being an adoptee	5	0.011	0.005	0.012
	44	Cultural racism	6	0.011	0.003	0.018
	45	Prescription drug abuse	6	0.011	0.008	0.017
	46	Having an Education and Health Care Plan (EHCP)	5	0.011	0.009	0.026
	47	Failure to attend three or more planned health or social care appointments	6	0.011	0.008	0.024
	48	Maternal use of psychotropics during pregnancy	5	0.011	0.004	0.016
	49	Maternal alcohol use during pregnancy	6	0.011	0.003	0.015
	50	Ethnic minority in low ethnic density area	6	0.011	0.003	0.016
	51	Special Educational Needs (SEN)	6	0.011	0.006	0.012
	52	Quality of school climate (e.g. relating to school connectedness, feelings of safety in school, perception of school, adult-student relationships, morale)	6	0.011	0.006	0.016
	53	Poverty	6	0.011	0.004	0.013
	54	Poor educational attainment	6	0.011	0.008	0.014
	55	Intellectual disability	6	0.010	0.003	0.018
=	56	Poor quality or a lack of social-emotional learning programmes in pre-school	5	0.010	0.004	0.015
=	56	Maternal depression during pregnancy	5	0.010	0.004	0.012

58	Physical disability	6	0.010	0.005	0.012
59	Maternal psychosis (perinatal or pre-natal)	5	0.010	0.006	0.015
60	Negative previous experiences of services	6	0.010	0.009	0.020
61	Being a young parent	6	0.010	0.003	0.013
62	Household overcrowding	6	0.010	0.003	0.012
63	Family financial problems	6	0.010	0.005	0.012
64	Area deprivation (area code)	6	0.010	0.004	0.016
65	Food poverty	6	0.010	0.003	0.012
66	Minority gender identity	4	0.010	0.002	0.017
67	Racial bias in obstetric care	5	0.010	0.001	0.014
68	School-level deprivation (e.g. proportion eligible for free school meals)	6	0.009	0.002	0.011
69	Personal direct experience of natural disaster	6	0.009	0.005	0.012
70	Living in an area with high crime levels	6	0.009	0.001	0.013
71	Increased pressure/stress for teachers (e.g. insufficient pay/resources and poor leadership)	6	0.009	0.002	0.015
72	Language impairment in primary caregiver(s)	6	0.009	0.001	0.015
73	Unemployment of the individual	6	0.008	0.005	0.013
74	Trapped during earthquake	5	0.008	0.006	0.014
75	Minority sexuality	5	0.008	0.002	0.015
76	Primary caregiver(s) parenting styles (strict/rigid/conventional)	6	0.008	0.001	0.021
77	Hearing impairment causing disability (e.g. deafness)	6	0.008	0.002	0.013
78	Primary caregiver(s) unemployment	6	0.008	0.001	0.010
79	Social-communication problems	6	0.007	0.005	0.012
80	Air pollution	6	0.007	0.002	0.014
81	Participation in the Free-Lunch Program	6	0.007	0.003	0.010
82	Low education level of primary caregiver(s)	6	0.007	0.004	0.011
83	School composition (e.g. size/headcount, gender proportions, ethnicity proportions)	4	0.007	0.002	0.011
84	Multi-generational families within the same home	6	0.006	0.000	0.008
85	Migration from another country	6	0.006	0.001	0.011
86	Visual impairment causing disability (e.g. blindness/partial sightedness)	5	0.006	0.003	0.012
= 87	Serving in the military	3	0.006	0.006	0.012

=	87	Missed ante-natal visits	5	0.006	0.002	0.011
	89	English as an additional language	6	0.006	0.000	0.015
	90	Nitrous oxide use	2	0.006	0.003	0.009
	91	Digital exclusion	4	0.006	0.004	0.013
	92	Low socioeconomic status	6	0.006	0.002	0.013
	93	Remoteness of living	6	0.006	0.000	0.013
	94	Low education level of caregiver(s) (other than primary caregiver(s))	6	0.005	0.001	0.011
	95	Urbanicity	5	0.005	0.001	0.011
	96	Ethnicity	5	0.005	0.002	0.010
	97	Climate change	5	0.005	0.002	0.010
	98	Belonging to a religious minority	6	0.005	0.000	0.011
	99	Belonging to a traveller community	5	0.004	0.001	0.010
	100	Religiosity	5	0.003	0.000	0.007
	101	Religiosity of caregiver(s)	6	0.001	0.000	0.011
	102	Being a second generation immigrant	6	0.001	0.000	0.011

Range: 2 - 6

Headers: **CI** = confidence intervals

Ψ Of note, the risk factor 'Experience of bereavement during a traumatic event' was accidentally missed from the main framework (domains 1-7) and only features in domain 8. As such, there are actually 288 unique risk factors in the whole framework but only 287 in the main framework (hence, 287 was used as the reported total).

9.1.2 Appendix A.2 – Unranked risk factors

Table 53: Risk factors which no respondent was able to rate; results for domains 1-8

Domain	Unrated risk factors
Social and Environmental	– Sub-total: 0
Behavioural	– Sub-total: 0
Education and Employment	– Sub-total: 0
Biomarkers	CD14 levels
Biomarkers	High levels of indoleamine-2,3-dioxygenase (IDO)
Biomarkers	High levels of tryptophan-2,3-dioxygenase (TDO)
Biomarkers	High peripheral manganese
Biomarkers	High permeability of blood-brain barrier
Biomarkers	Increased levels of chemokines
Biomarkers	Increased levels of eicosanoids
Biomarkers	Increased quinolinic acid (QUIN)
Biomarkers	Kynurenine/tryptophan ratio
Biomarkers	Low levels of B vitamins
Biomarkers	Low or high levels of GDNF (i.e. neurotrophic factor)
Biomarkers	Low or high levels of Tumour Necrosis Factor alpha (TNF- α)
Biomarkers	Neutrophil-lymphocyte ratio (NLR)
Biomarkers	Reduced kynurenic acid (KYNA)
	Sub-total: 14
Physical Health	Maternal acetaminophen (paracetamol) use during pregnancy
	Sub-total: 1
Psychological and Mental Health	– Sub-total: 0
Patterns of Service Use	– Sub-total: 0
Factors Identified to be Particularly Relevant to Under-Served Populations	– Sub-total: 0
	Grand total of unrated risk factors: 15

9.1.3 Appendix A.3 – Heat maps for domains 1-8

Key for all life course stage heat maps in this section: **S** = Society-level; **F/C** = Family/caregiver-level; **I** = Individual-level.

Note to the reader: a few risk factors are logically impossible at certain life course stages; however, all collected data are shown in the heat maps for completeness. (It seems likely these stages were accidentally marked by respondents who ticked the option ‘all life course stages’ to save time).

Figure 24: Heat map to illustrate where in the life course exposure to risk factors is most harmful for young people’s mental health outcomes (Domain 1: Social and Environmental; society- and family/caregiver-level factors). Note: due to the number of risk factors in this domain, it has been split across two figures.]

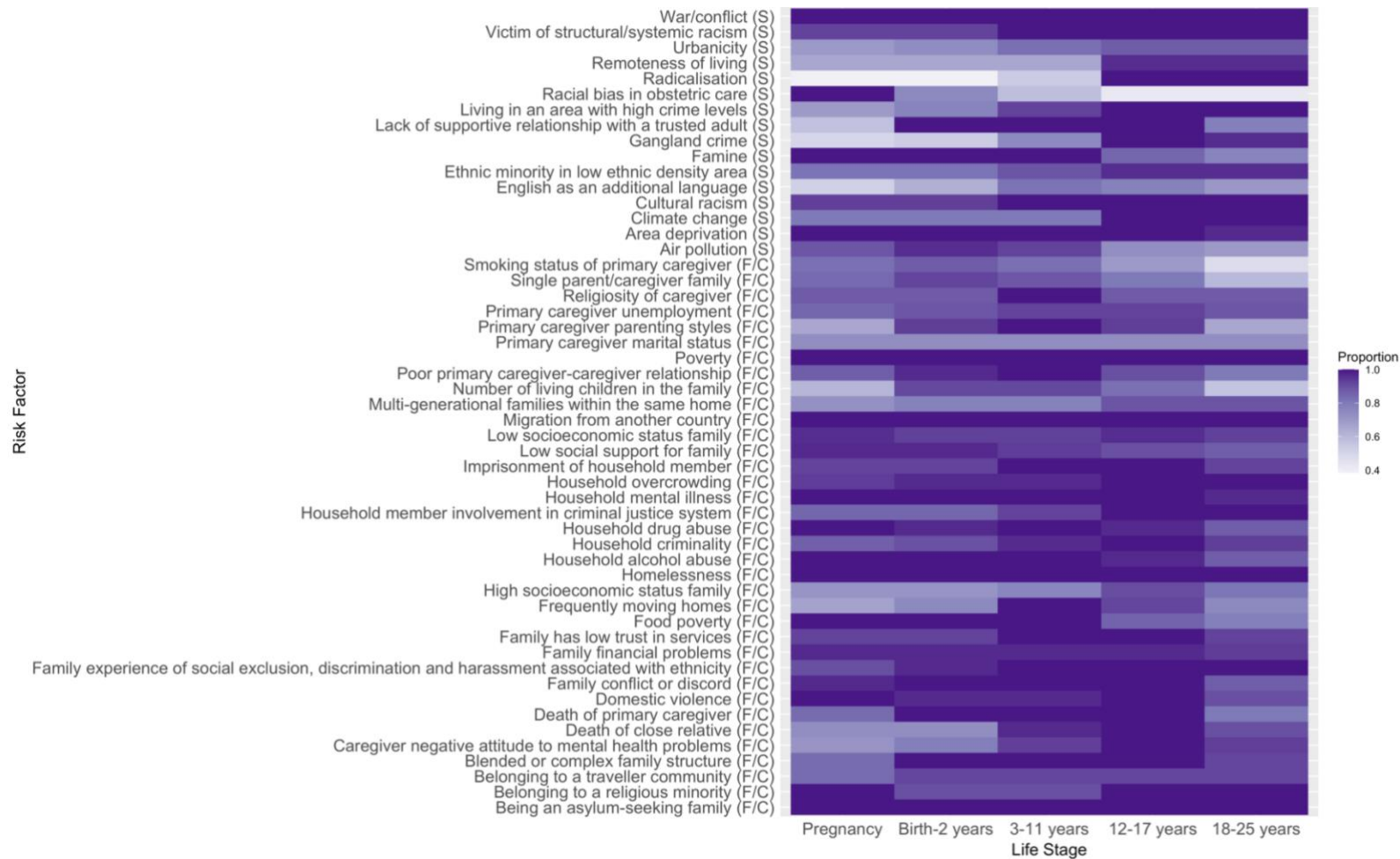


Figure 24 (continued): Heat map to illustrate where in the life course exposure to risk factors is most harmful for young people's mental health outcomes (Domain 1: Social and Environmental; individual-level factors)

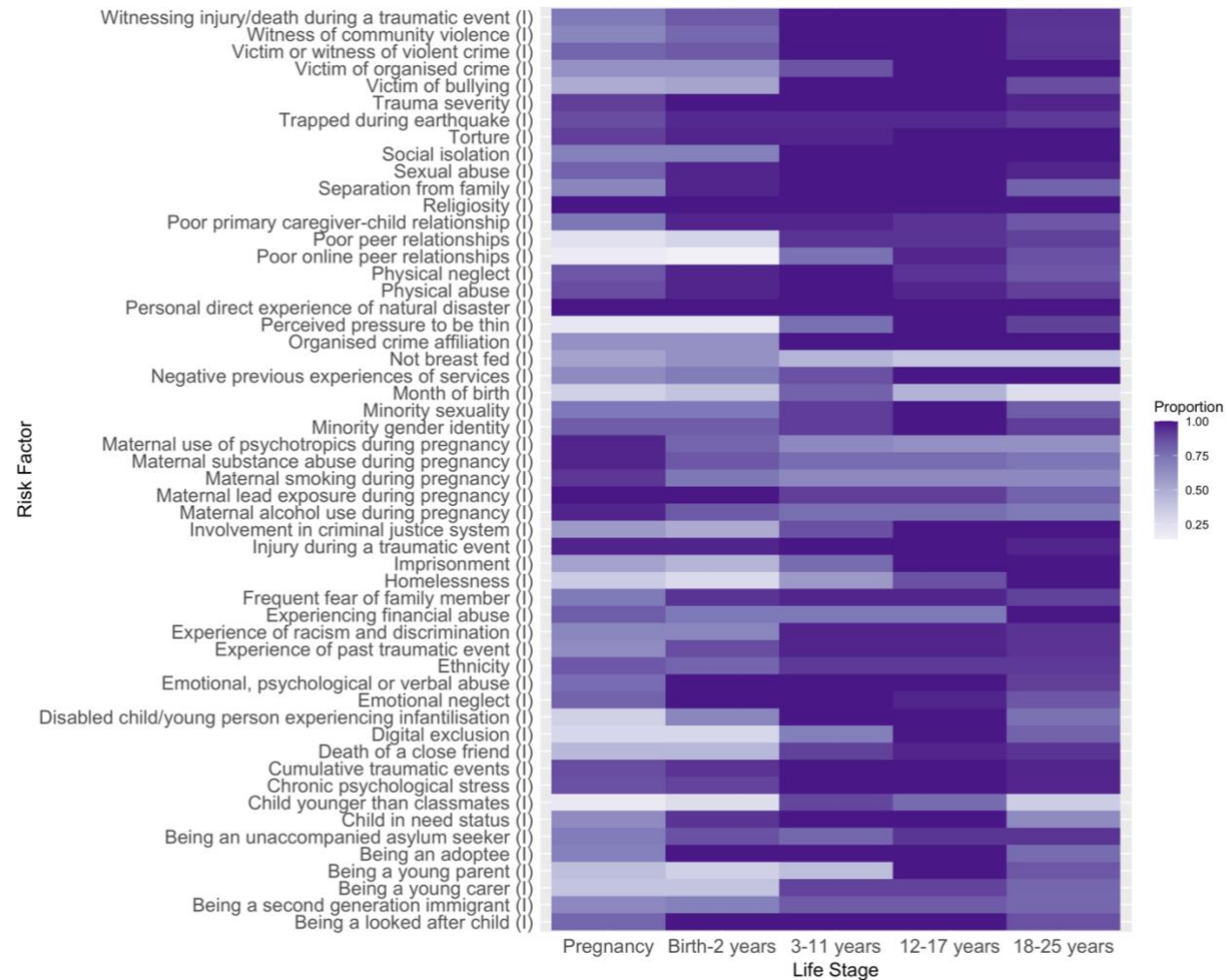


Figure 25: Heat map to illustrate where in the life course exposure to risk factors is most harmful for young people's mental health outcomes (Domain 2: Behavioural)

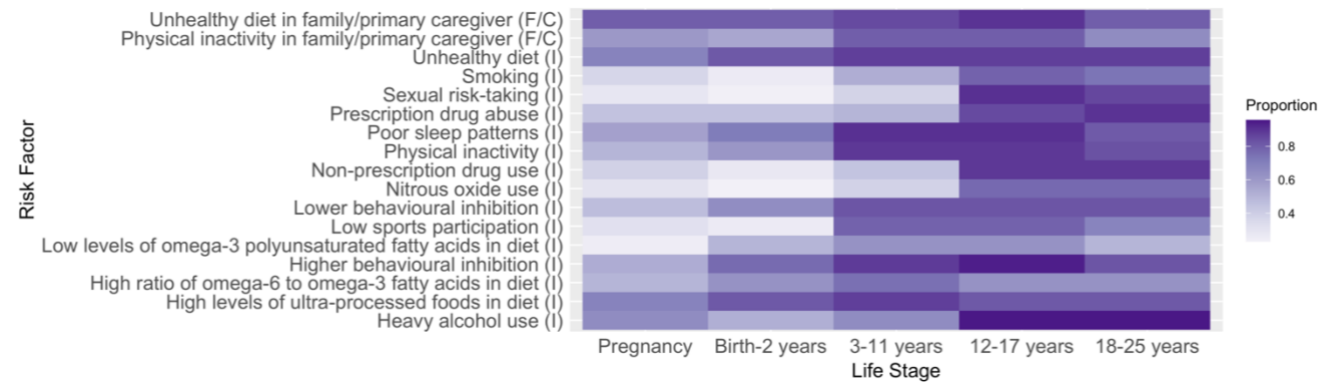


Figure 26: Heat map to illustrate where in the life course exposure to risk factors is most harmful for young people's mental health outcomes (Domain 3: Education and Employment)

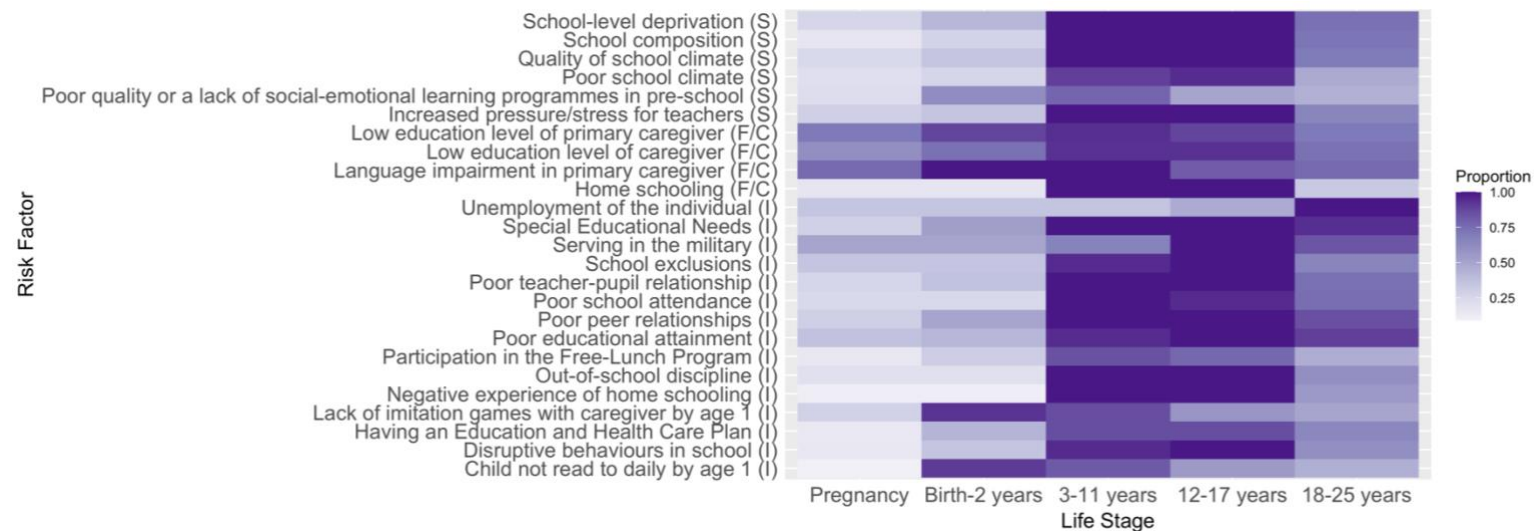


Figure 27: Heat map to illustrate where in the life course exposure to risk factors is most harmful for young people's mental health outcomes (Domain 4: Biomarkers)

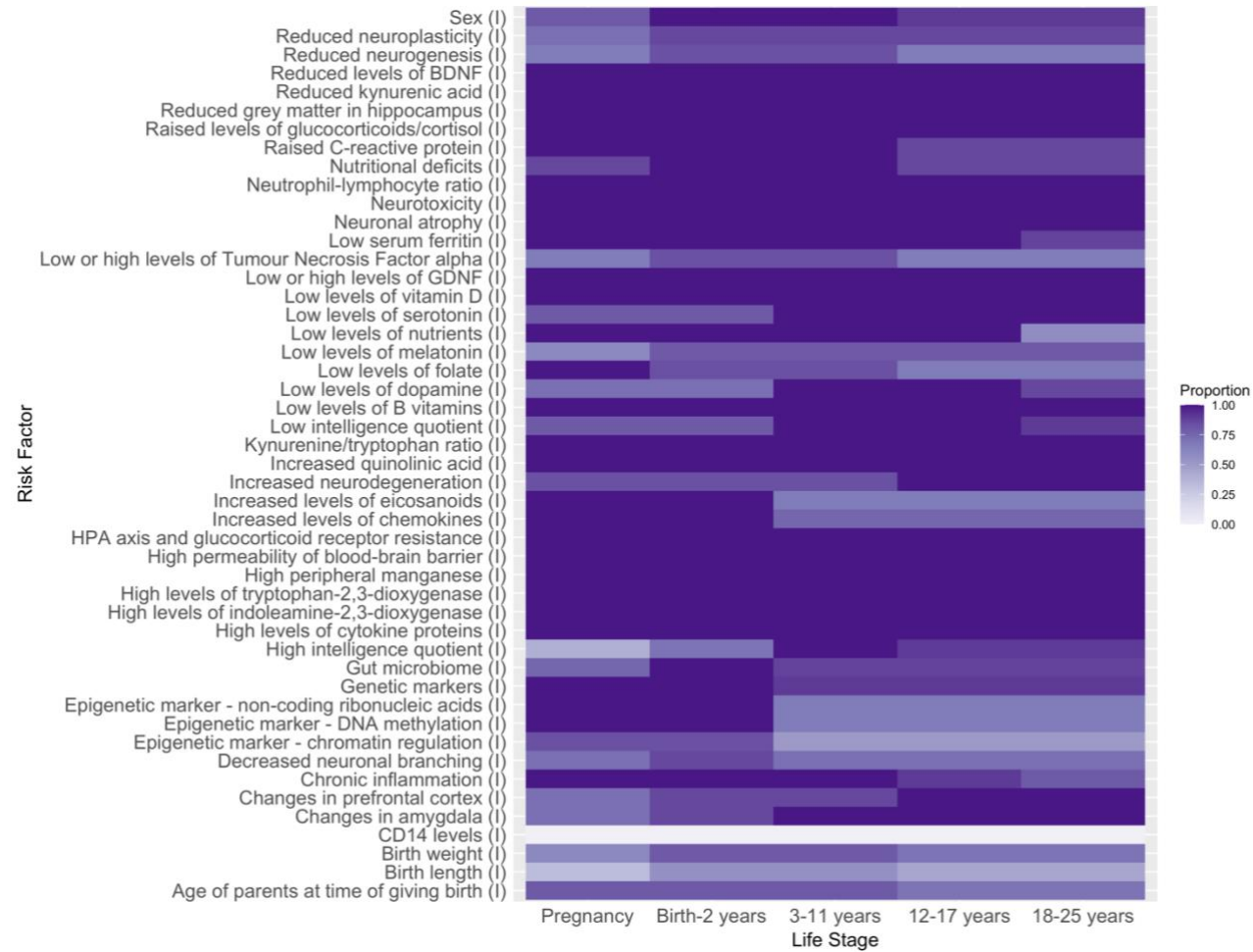


Figure 28: Heat map to illustrate where in the life course exposure to risk factors is most harmful for young people's mental health outcomes (Domain 5: Physical Health)

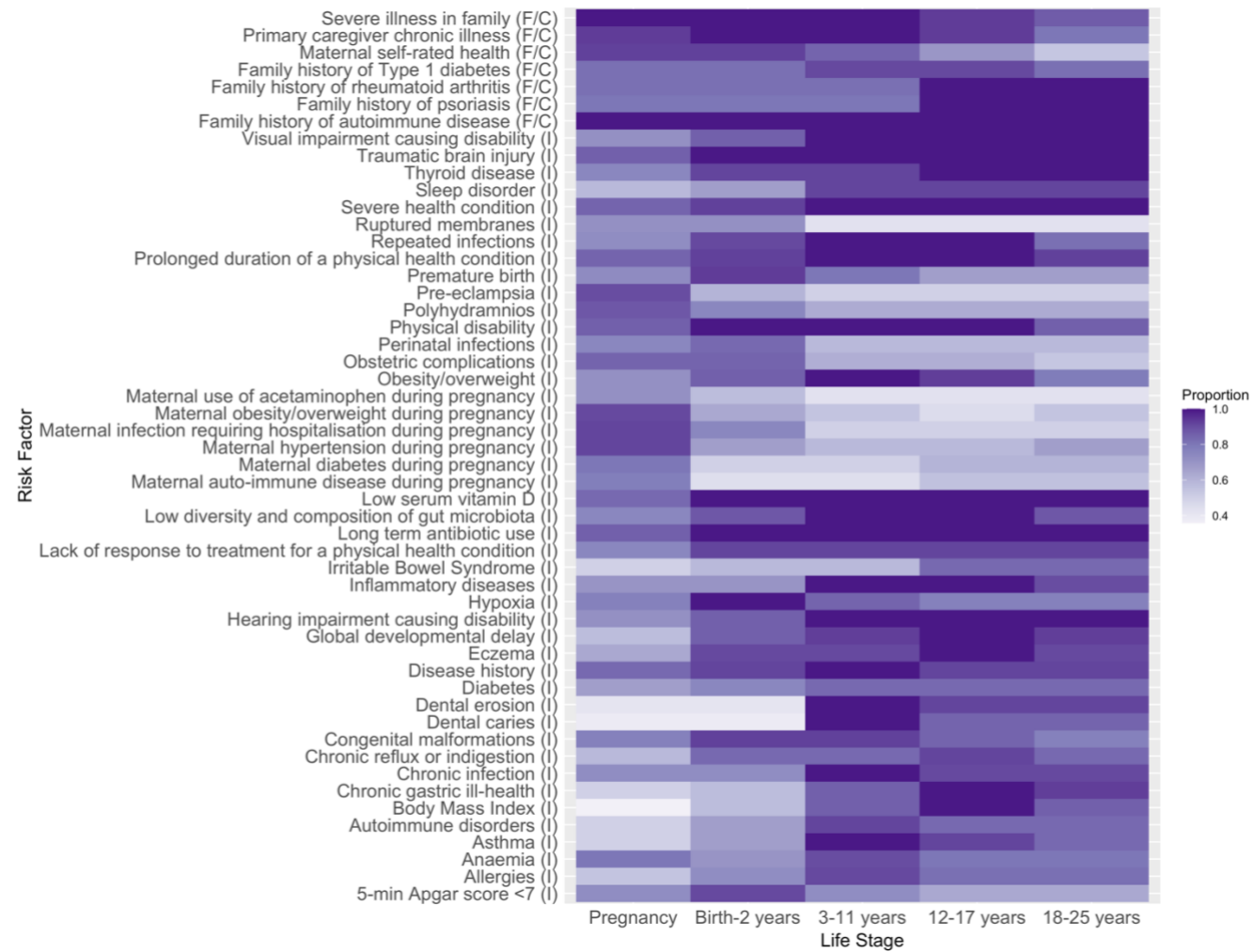


Figure 29: Heat map to illustrate where in the life course exposure to risk factors is most harmful for young people's mental health outcomes (Domain 6: Psychological and Mental Health)

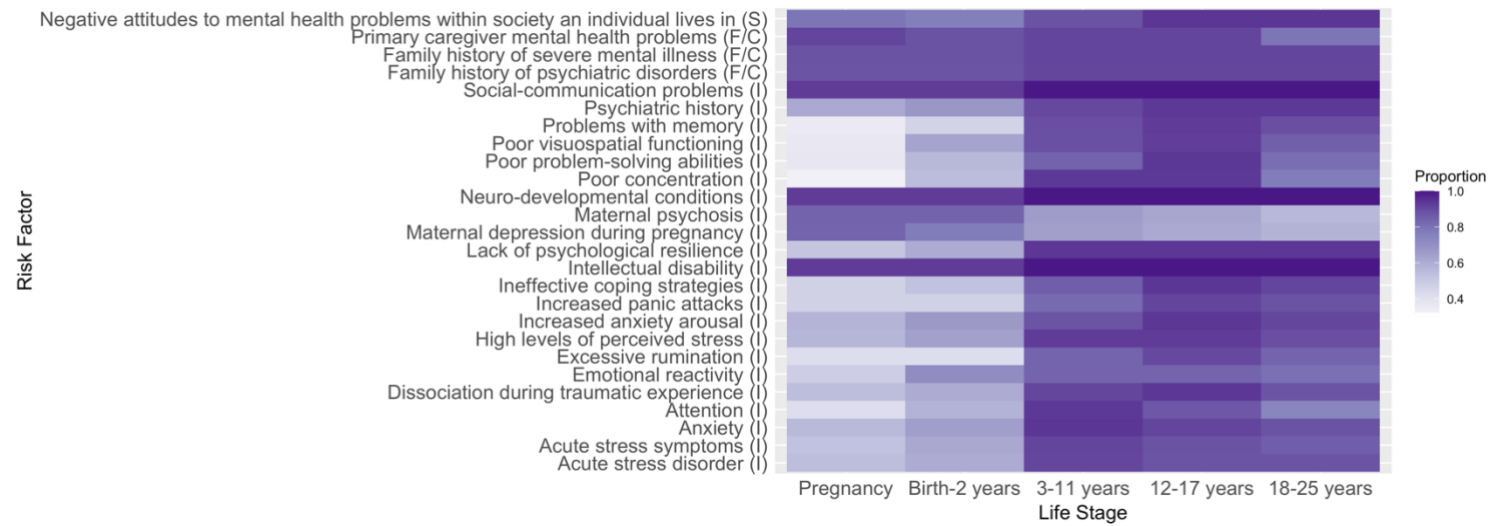


Figure 30: Heat map to illustrate where in the life course exposure to risk factors is most harmful for young people's mental health outcomes (Domain 7: Patterns of Service Use)

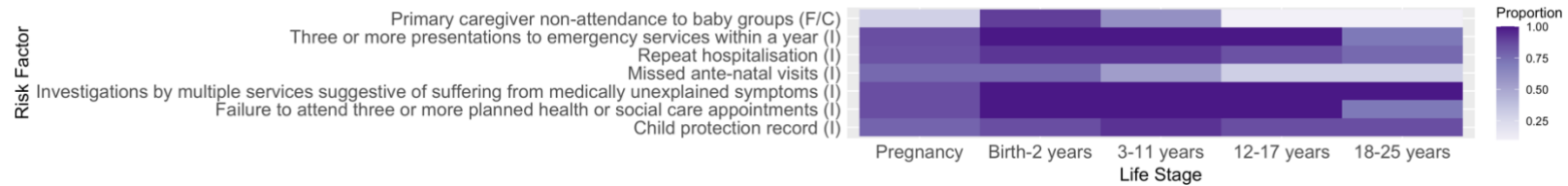


Figure 31: Heat map to illustrate where in the life course exposure to risk factors is most harmful for young people's mental health outcomes (Domain 8: Factors Identified to be Particularly Relevant to Under-Served Populations; society- and family/caregiver-level factors). Note: due to the number of risk factors in this domain, it has been split across two figures.]

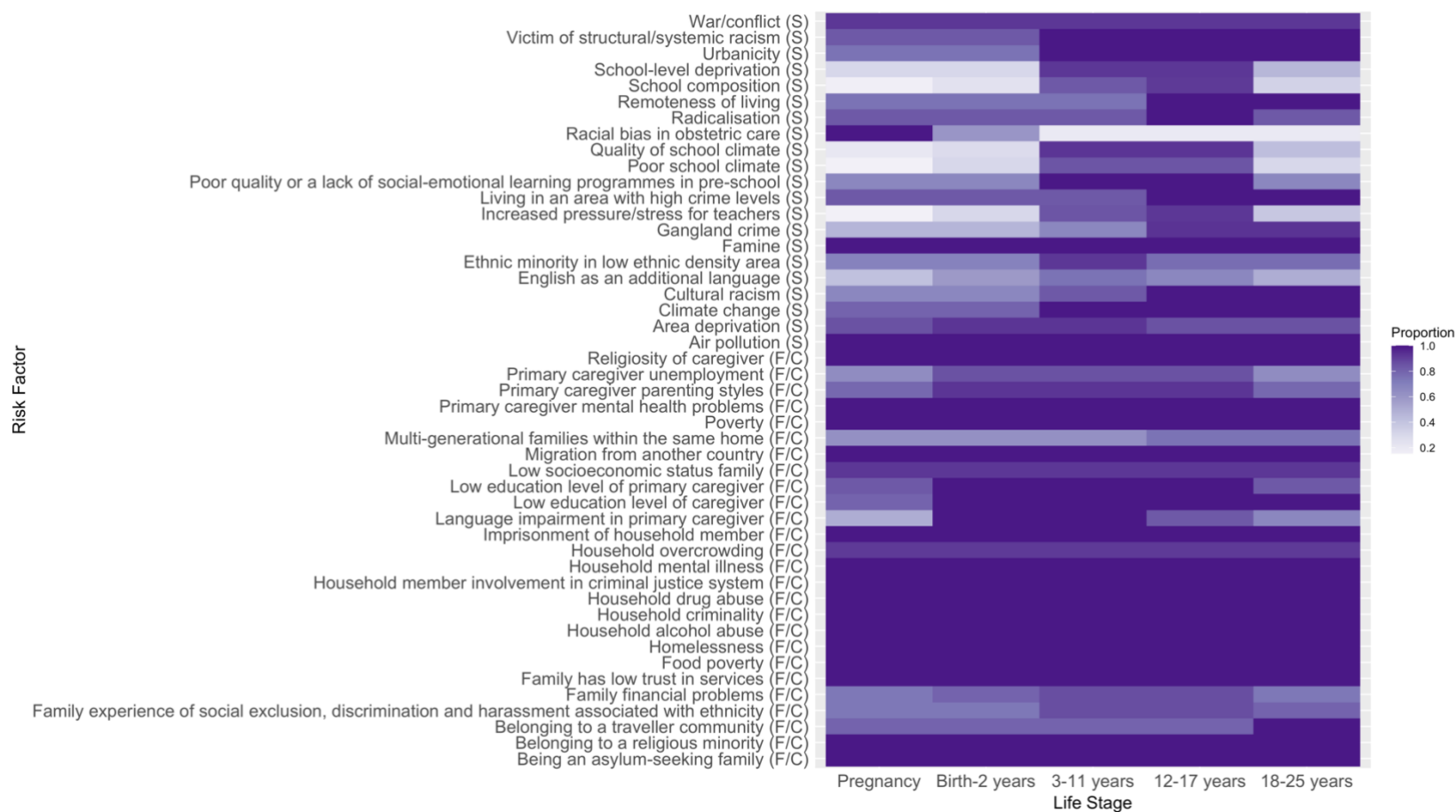
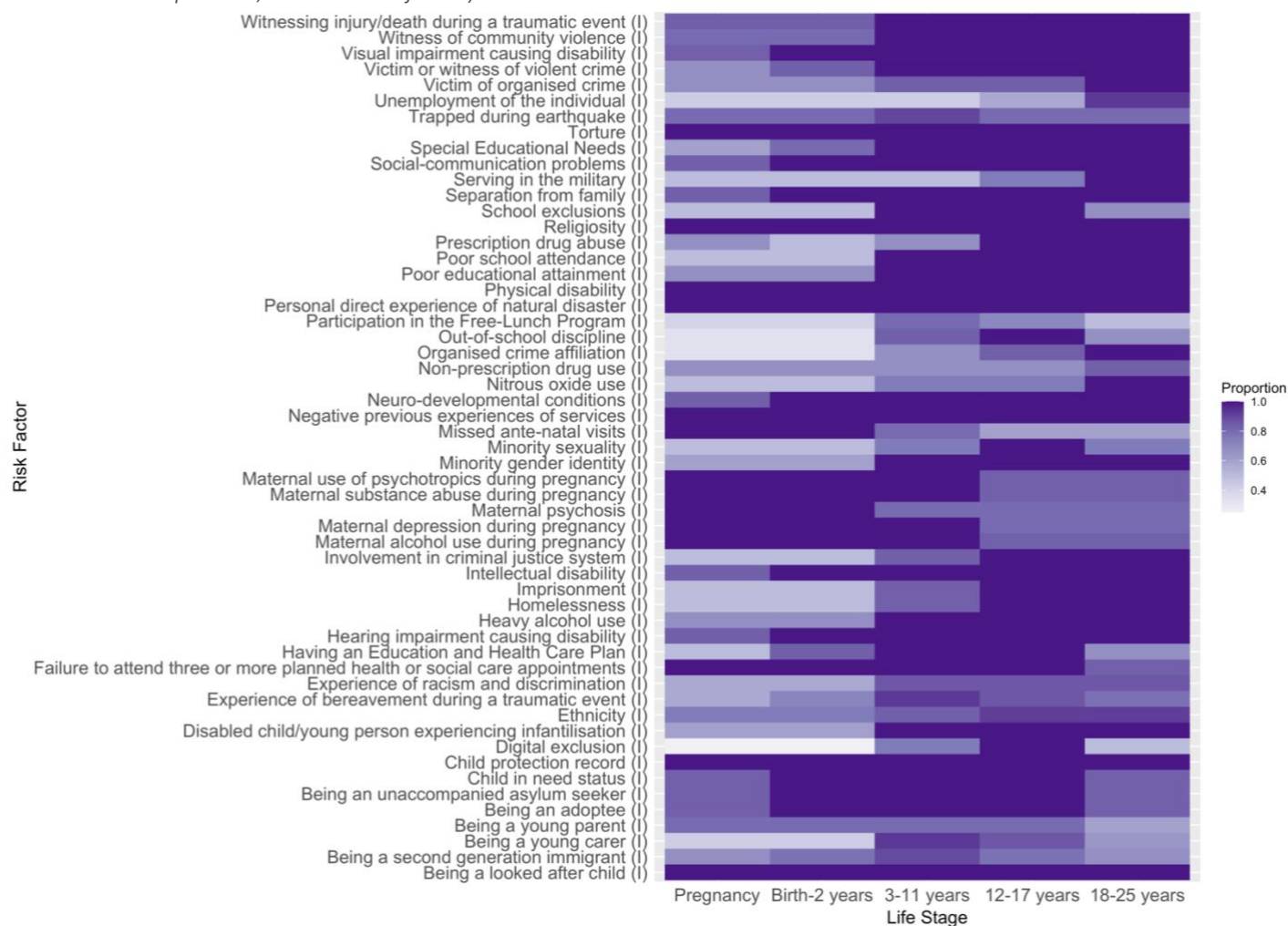


Figure 31 (continued): Heat map to illustrate where in the life course exposure to risk factors is most harmful for young people's mental health outcomes (Domain 8: Factors Identified to be Particularly Relevant to Under-Served Populations; individual-level factors)



9.1.4 Appendix A.4 – Final theoretical framework of risk factors

Figure 32: Final theoretical framework based on the Delphi consensus-building process

Domain 1: Social and Environmental 			
Rank within Domain	Risk Factor	Level	Number of Raters (N)
1	Being a looked after child (LAC)	Individual	14
2	Torture	Individual	13
3	Sexual abuse	Individual	16
4	Lack of supportive relationship(s) with a trusted adult	Society	15
=5	Poor primary caregiver-caregiver relationship	Family/Caregiver	16
=5	Cumulative traumatic events	Individual	16
=7	Domestic violence	Family/Caregiver	16
=7	Trauma severity	Individual	14
9	Emotional, psychological or verbal abuse	Individual	16
10	Emotional neglect	Individual	16
11	Victim of organised crime (e.g. commercial sexual exploitation or via county lines)	Individual	13
=12	Household drug abuse	Family/Caregiver	16
=12	Poor primary caregiver-child relationship	Individual	16
14	Physical abuse	Individual	16
15	Household mental illness	Family/Caregiver	16
16	Family conflict or discord	Family/Caregiver	16
17	Death of primary caregiver(s)	Family/Caregiver	16
18	Caregiver negative attitude to mental health problems	Family/Caregiver	16
19	Separation from family (e.g. out-of-home care)	Individual	15
=20	Homelessness	Family/Caregiver	16
=20	Chronic psychological stress	Individual	16
22	Household alcohol abuse	Family/Caregiver	16
23	Family experience of social exclusion, discrimination and harassment associated with ethnicity	Family/Caregiver	14
24	Victim or witness of violent crime	Individual	13
25	Social isolation	Individual	16
26	Physical neglect	Individual	16
27	Witnessing injury/death during a traumatic event	Individual	14
28	Being an unaccompanied asylum seeker	Individual	15
=29	Being an asylum-seeking family	Family/Caregiver	14
=29	Victim of bullying	Individual	16
=31	Experience of racism and discrimination	Individual	15
=31	Child in need (CIN) status	Individual	15
33	Maternal substance abuse during pregnancy	Individual	14
34	Imprisonment	Individual	14
35	Experience of past traumatic event	Individual	16
36	Frequent fear of family member	Individual	16
=37	Involvement in criminal justice system	Individual	15
=37	Homelessness (young person has left home)	Individual	15
39	War/conflict	Society	13
40	Victim of structural/systemic racism	Society	13

41 Witness of community violence	Individual	13
42 Household criminality	Family/Caregiver	16
43 Area deprivation (area code)	Society	15
44 Injury during a traumatic event	Individual	14
45 Household member involvement in criminal justice system	Family/Caregiver	16
46 Disabled child/young person experiencing infantilisation	Individual	10
47 Maternal lead exposure during pregnancy	Individual	8
48 Maternal use of psychotropics during pregnancy	Individual	11
49 Imprisonment of household member	Family/Caregiver	14
50 Maternal alcohol use during pregnancy	Individual	15
51 Poor peer relationships	Individual	16
52 Cultural racism	Society	14
53 Organised crime affiliation	Individual	12
54 Death of a close friend	Individual	16
55 Trapped during earthquake	Individual	11
56 Family has low trust in services	Family/Caregiver	15
57 Famine	Society	12
58 Family financial problems	Family/Caregiver	15
59 Low social support for family	Family/Caregiver	16
60 Being an adoptee	Individual	15
61 Gangland crime	Society	13
62 Being a young carer	Individual	16
63 Frequently moving homes	Family/Caregiver	15
=64 Ethnic minority in low ethnic density area	Society	13
=64 Experiencing financial abuse	Individual	13
66 Personal direct experience of natural disaster	Individual	16
67 Household overcrowding	Family/Caregiver	14
68 Perceived pressure to be thin	Individual	16
69 Poverty	Family/Caregiver	16
70 Minority gender identity	Individual	11
71 Food poverty	Family/Caregiver	13
72 Poor online peer relationships	Individual	16
73 Minority sexuality	Individual	12
74 Death of close relative (excluding primary caregiver(s))	Family/Caregiver	16
75 Being a young parent	Individual	16
76 Radicalisation	Society	12
77 English as an additional language	Society	13
78 Racial bias in obstetric care	Society	11
79 Maternal smoking during pregnancy	Individual	12
80 Low socioeconomic status family	Family/Caregiver	16
81 Primary caregiver(s) parenting styles (strict/rigid/conventional)	Family/Caregiver	16
82 Living in an area with high crime levels	Society	13
83 Migration from another country	Family/Caregiver	14
84 Remoteness of living	Society	12

	85 Belonging to a traveller community	Family/Caregiver	14
	86 Negative previous experiences of services	Individual	16
	87 Belonging to a religious minority	Family/Caregiver	14
	88 Air pollution	Society	12
	89 Blended or complex family structure	Family/Caregiver	16
	90 Primary caregiver(s) unemployment	Family/Caregiver	16
	91 Digital exclusion	Individual	11
	92 Being a second generation immigrant	Individual	13
	93 Number of living children in the family	Family/Caregiver	15
	94 Urbanicity	Society	12
	95 Climate change	Society	11
	96 Ethnicity	Individual	11
	97 Smoking status of primary caregiver(s)	Family/Caregiver	13
	98 Multi-generational families within the same home	Family/Caregiver	13
	99 Religiosity of caregiver(s)	Family/Caregiver	13
	100 Child younger than classmates	Individual	13
	101 Single parent/caregiver family	Family/Caregiver	16
	102 Religiosity	Individual	12
	103 Not breast fed	Individual	10
	104 Month of birth	Individual	12
	105 High socioeconomic status family	Family/Caregiver	15
	106 Primary caregiver(s) marital status	Family/Caregiver	16
Domain 2: Behavioural 			
Rank within Domain	Risk Factor	Level	Number of Raters (N)
1	Heavy alcohol use	Individual	14
2	Poor sleep patterns	Individual	14
3	Sexual risk-taking	Individual	14
4	Prescription drug abuse	Individual	11
5	Higher behavioural inhibition	Individual	10
6	Non-prescription drug use	Individual	12
7	Frequent social media use	Individual	14
8	Physical inactivity	Individual	13
9	Unhealthy diet in family/primary caregiver(s)	Family/Caregiver	14
10	Smoking	Individual	13
11	Physical inactivity in family/primary caregiver(s)	Family/Caregiver	14
12	Nitrous oxide use	Individual	8
13	High levels of ultra-processed foods in diet	Individual	8
14	Unhealthy diet	Individual	13
15	Lower behavioural inhibition	Individual	10
16	Foods high in trans fats in diet	Individual	10
17	Excessive sports participation	Individual	12
18	Low sports participation	Individual	12

	19 Diet low in plant-matter diversity	Individual	8
	20 Excessive physical activity	Individual	12
	21 High ratio of omega-6 to omega-3 fatty acids in diet	Individual	6
	22 Low levels of omega-3 polyunsaturated fatty acids in diet	Individual	6
	23 Diet low in plant-matter	Individual	9
Domain 3: Education and Employment 			
Rank within Domain	Risk Factor	Level	Number of Raters (N)
	1 School exclusions	Individual	7
	2 Quality of school climate (e.g. relating to school connectedness, feelings of safety in school, perception of school, adult-student relationships, morale)	Society	6
	=3 Disruptive behaviours in school (e.g. defiance and non-compliance)	Individual	7
	=3 Poor peer relationships	Individual	7
	=3 Poor school attendance	Individual	7
	=3 Poor teacher-pupil relationship	Individual	7
	7 Having an Education and Health Care Plan (EHCP)	Individual	7
	8 Out-of-school discipline (e.g. suspension and expulsion)	Individual	6
	9 Poor school climate (e.g. Ofsted weightings)	Society	6
	10 Special Educational Needs (SEN)	Individual	7
	11 Poor quality or a lack of social-emotional learning programmes in pre-school	Society	7
	=12 Home schooling (not by choice)	Family/Caregiver	7
	=12 Negative experience of home schooling	Individual	7
	14 Increased pressure/stress for teachers (e.g. insufficient pay/resources and poor leadership)	Society	6
	15 Language impairment in primary caregiver(s)	Family/Caregiver	7
	16 Poor educational attainment	Individual	7
	17 Unemployment of the individual	Individual	6
	18 Lack of imitation games with caregivers by age 1	Individual	5
	19 Serving in the military	Individual	3
	20 Low education level of primary caregiver(s)	Family/Caregiver	7
	21 Child not read to daily by age 1	Individual	6
	22 School-level deprivation (e.g. proportion eligible for free school meals)	Society	6
	23 Participation in the Free-Lunch Program	Individual	6
	24 School composition (e.g. size/headcount, gender proportions, ethnicity proportions)	Society	5
	25 Low education level of caregiver(s) (other than primary caregiver(s))	Family/Caregiver	6
Domain 4: Biomarkers 			
Rank within Domain	Risk Factor	Level	Number of Raters (N)
	1 Low intelligence quotient (IQ)	Individual	3
	2 Genetic markers	Individual	3
	3 Sex (biological)	Individual	3
	4 Nutritional deficits	Individual	2
	5 Neurotoxicity	Individual	3
	6 Neuronal atrophy	Individual	2

7 Increased neurodegeneration	Individual	3
8 Reduced neuroplasticity	Individual	2
9 Low levels of dopamine	Individual	2
10 Low levels of nutrients	Individual	2
11 Low levels of serotonin	Individual	2
12 Reduced neurogenesis	Individual	2
13 HPA axis and glucocorticoid receptor resistance	Individual	1
14 Low levels of folate	Individual	1
15 Reduced levels of BDNF (i.e. neurotrophic factor)	Individual	1
16 Reduced grey matter in hippocampus	Individual	2
17 Raised levels of glucocorticoids/cortisol	Individual	2
18 High levels of cytokine proteins (e.g. interleukin-1 [IL-1]; interleukin-6 [IL-6])	Individual	1
19 Birth weight	Individual	3
20 Raised C-reactive protein (CRP)	Individual	2
21 Low levels of vitamin D	Individual	2
22 Decreased neuronal branching	Individual	2
23 Low levels of melatonin	Individual	1
24 Low serum ferritin	Individual	2
25 Changes in prefrontal cortex (e.g. reduced total volume; low myelination; low white matter; increased middle inferior and ventral regions and superior/dorsal regions)	Individual	2
=26 Age of parents at time of giving birth	Individual	3
=26 High intelligence quotient (IQ)	Individual	3
=28 Epigenetic marker - DNA methylation	Individual	1
=28 Epigenetic marker - non-coding ribonucleic acids	Individual	1
28 Gut microbiome (reduced diversity and reduced populations of certain bacteria)	Individual	1
31 Epigenetic marker - chromatin regulation	Individual	1
32 Chronic inflammation	Individual	1
33 Changes in amygdala (e.g. reduced volume)	Individual	2
34 Birth length	Individual	2
_ CD14 levels	Individual	0
_ High levels of indoleamine-2,3-dioxygenase (IDO)	Individual	0
_ High levels of tryptophan-2,3-dioxygenase (TDO)	Individual	0
_ High peripheral manganese	Individual	0
_ High permeability of blood-brain barrier	Individual	0
_ Increased levels of chemokines	Individual	0
_ Increased levels of eicosanoids	Individual	0
_ Increased quinolinic acid (QUIN)	Individual	0
_ Kynurenine/tryptophan ratio	Individual	0
_ Low levels of B vitamins	Individual	0
_ Low or high levels of GDNF (i.e. neurotrophic factor)	Individual	0
_ Low or high levels of Tumour Necrosis Factor alpha (TNF- α)	Individual	0
_ Neutrophil-lymphocyte ratio (NLR)	Individual	0
_ Reduced kynurenic acid (KYNA)	Individual	0

Domain 5: Physical Health 			
Rank within Domain	Risk Factor	Level	Number of Raters (N)
	1 Traumatic brain injury	Individual	6
	2 Primary caregiver(s) chronic (long lasting) illness	Family/Caregiver	6
	3 Severe health condition	Individual	6
	4 Severe illness in family	Family/Caregiver	6
	5 Sleep disorder	Individual	6
	6 Physical disability	Individual	6
	7 Global developmental delay	Individual	6
	8 Prolonged duration of a physical health condition	Individual	5
	9 Irritable Bowel Syndrome (IBS)	Individual	5
	10 Lack of response to treatment for a physical health condition	Individual	4
	11 Diabetes	Individual	6
	12 Hearing impairment causing disability (e.g. deafness)	Individual	6
	13 Autoimmune disorders (e.g. rheumatoid arthritis)	Individual	6
	14 Hypoxia (at birth)	Individual	4
	15 Maternal obesity/overweight during pregnancy	Individual	2
	16 Visual impairment causing disability (e.g. blindness/partial sightedness)	Individual	5
	17 Thyroid disease	Individual	5
	18 Congenital malformations	Individual	5
	19 5-min Apgar score <7	Individual	6
	20 Asthma	Individual	6
	21 Anaemia	Individual	6
	22 Premature birth	Individual	6
	=23 Low diversity and composition of gut microbiota	Individual	3
	=23 Repeated infections	Individual	5
	25 Pre-eclampsia	Individual	4
	26 Inflammatory diseases (e.g. Lyme disease)	Individual	5
	=27 Maternal hypertension during pregnancy	Individual	1
	=27 Maternal infection requiring hospitalisation during pregnancy	Individual	1
	=27 Maternal diabetes during pregnancy	Individual	1
	=27 Chronic (long lasting) infection (e.g. Lyme disease, periodontal disease)	Individual	5
	=31 Low serum vitamin D	Individual	5
	=31 Maternal auto-immune disease during pregnancy	Individual	1
	33 Perinatal infections (e.g. cytomegalovirus)	Individual	6
	34 Family history of autoimmune disease	Family/Caregiver	6
	35 Chronic (long lasting) gastric ill-health (e.g. inflammatory bowel disease)	Individual	5
	36 Obstetric complications (other)	Individual	4
	37 Disease history	Individual	3
	38 Dental caries (tooth decay)	Individual	6
	39 Chronic (long lasting) reflux or indigestion	Individual	5
	40 Allergies (e.g. non-IgE-mediated food allergies, pollen allergies)	Individual	6

	41 Family history of psoriasis	Family/Caregiver	4
	42 Obesity/overweight	Individual	4
	43 Body Mass Index (BMI)	Individual	5
	44 Eczema	Individual	6
	45 Long term antibiotic use	Individual	4
	46 Family history of Type 1 diabetes	Family/Caregiver	6
	47 Family history of rheumatoid arthritis	Family/Caregiver	4
	48 Maternal self-rated health (prior to pregnancy)	Family/Caregiver	4
	49 Dental erosion	Individual	4
	50 Polyhydramnios	Individual	3
	51 Ruptured membranes (at birth)	Individual	4
	_ Maternal acetaminophen (paracetamol) use during pregnancy	Individual	0
Domain 6: Psychological and Mental Health 			
Rank within Domain	Risk Factor	Level	Number of Raters (N)
	1 Family history of severe mental illness (e.g. psychosis)	Family/Caregiver	14
	2 Primary caregiver(s) mental health problems	Family/Caregiver	14
	3 Psychiatric history	Individual	14
	4 Family history of psychiatric disorders	Family/Caregiver	14
	5 Social-communication problems	Individual	14
	6 Neuro-developmental conditions (e.g. autism)	Individual	13
	7 Increased panic attacks	Individual	13
	8 Anxiety (as a predictor of further mental health problems)	Individual	14
	=9 High levels of perceived stress	Individual	13
	=9 Ineffective coping strategies	Individual	13
	11 Maternal psychosis (perinatal or pre-natal)	Individual	12
	12 Lack of psychological resilience	Individual	14
	13 Attention (as a predictor of further mental health problems)	Individual	13
	14 Intellectual disability	Individual	12
	15 Increased anxiety arousal	Individual	13
	16 Dissociation during traumatic experience	Individual	12
	17 Acute stress symptoms (anxiety, avoidance or depression - as a predictor of further mental health problems)	Individual	14
	18 Acute stress disorder (as a predictor of further mental health problems)	Individual	14
	19 Excessive rumination	Individual	13
	20 Poor concentration	Individual	13
	21 Negative attitudes to mental health problems within society an individual lives in	Society	14
	22 Maternal depression during pregnancy	Individual	12
	23 Poor problem-solving abilities	Individual	13
	24 Emotional reactivity	Individual	14
	25 Poor visuospatial functioning	Individual	10
	26 Problems with memory	Individual	13

Domain 7: Patterns of Service Use 			
Rank within Domain	Risk Factor	Level	Number of Raters (N)
	1 Child protection record	Individual	6
	2 Investigations by multiple services suggestive of suffering from medically unexplained symptoms	Individual	7
	3 Failure to attend three or more planned health or social care appointments	Individual	7
	4 Three or more presentations to emergency services within a year	Individual	6
	5 Repeat hospitalisation	Individual	6
	6 Missed ante-natal visits	Individual	6
	7 Primary caregiver(s) non-attendance at baby groups	Family/Caregiver	7
Domain 8: Factors Identified to be Particularly Relevant to Under-Served Populations 			
Rank within Domain	Risk Factor	Level	Number of Raters (N)
	1 Being a looked after child (LAC)	Individual	5
	2 Child in need (CIN) status	Individual	5
	3 Torture	Individual	5
	4 Separation from family (e.g. out-of-home care)	Individual	6
	5 Child protection record	Individual	6
	6 Heavy alcohol use	Individual	6
	7 Victim of organised crime (e.g. commercial sexual exploitation or via county lines)	Individual	5
	8 Imprisonment	Individual	5
	9 Homelessness (young person has left home)	Individual	6
	10 Primary caregiver(s) mental health problems	Family/Caregiver	6
	11 Victim or witness of violent crime	Individual	6
	12 Experience of bereavement during a traumatic event	Individual	6
	13 Victim of structural/systemic racism	Society	6
	14 Being an asylum-seeking family	Family/Caregiver	6
	15 Homelessness	Family/Caregiver	6
	16 Household mental illness	Family/Caregiver	6
	17 War/conflict	Society	6
	=18 Gangland crime	Society	6
	=18 Family experience of social exclusion, discrimination and harassment associated with ethnicity	Family/Caregiver	6
	20 Witnessing injury/death during a traumatic event	Individual	6
	21 Neuro-developmental conditions (e.g. autism)	Individual	6
	22 Experience of racism and discrimination	Individual	6
	23 Disabled child/young person experiencing infantilisation	Individual	2
	24 Out-of-school discipline (e.g. suspension and expulsion)	Individual	6
	25 Being an unaccompanied asylum seeker	Individual	6
	26 Famine	Society	5
	=27 Household drug abuse	Family/Caregiver	6
	=27 Household member involvement in criminal justice system	Family/Caregiver	6
	29 Being a young carer	Individual	6

30 Radicalisation	Society	6
31 Organised crime affiliation	Individual	5
32 Household alcohol abuse	Family/Caregiver	6
33 Involvement in criminal justice system	Individual	6
34 Witness of community violence	Individual	6
35 School exclusions	Individual	6
36 Family has low trust in services	Family/Caregiver	6
37 Household criminality	Family/Caregiver	6
38 Imprisonment of household member	Family/Caregiver	5
39 Non-prescription drug use	Individual	6
40 Poor school attendance	Individual	6
41 Maternal substance abuse during pregnancy	Individual	6
42 Poor school climate (e.g. Ofsted weightings)	Society	6
43 Being an adoptee	Individual	5
44 Cultural racism	Society	6
45 Prescription drug abuse	Individual	6
46 Having an Education and Health Care Plan (EHCP)	Individual	5
47 Failure to attend three or more planned health or social care appointments	Individual	6
48 Maternal use of psychotropics during pregnancy	Individual	5
49 Maternal alcohol use during pregnancy	Individual	6
50 Ethnic minority in low ethnic density area	Society	6
51 Special Educational Needs (SEN)	Individual	6
52 Quality of school climate (e.g. relating to school connectedness, feelings of safety in school, perception of school, adult-student relationships, morale)	Society	6
53 Poverty	Family/Caregiver	6
54 Poor educational attainment	Individual	6
55 Intellectual disability	Individual	6
=56 Poor quality or a lack of social-emotional learning programmes in pre-school	Society	5
=56 Maternal depression during pregnancy	Individual	5
58 Physical disability	Individual	6
59 Maternal psychosis (perinatal or pre-natal)	Individual	5
60 Negative previous experiences of services	Individual	6
61 Being a young parent	Individual	6
62 Household overcrowding	Family/Caregiver	6
63 Family financial problems	Family/Caregiver	6
64 Area deprivation (area code)	Society	6
65 Food poverty	Family/Caregiver	6
66 Minority gender identity	Individual	4
67 Racial bias in obstetric care	Society	5
68 School-level deprivation (e.g. proportion eligible for free school meals)	Society	6
69 Personal direct experience of natural disaster	Individual	6
70 Living in an area with high crime levels	Society	6
71 Increased pressure/stress for teachers (e.g. insufficient pay/resources and poor leadership)	Society	6
72 Language impairment in primary caregiver(s)	Family/Caregiver	6
73 Unemployment of the individual	Individual	6

74 Trapped during earthquake	Individual	5
75 Minority sexuality	Individual	5
76 Primary caregiver(s) parenting styles (strict/rigid/conventional)	Family/Caregiver	6
77 Hearing impairment causing disability (e.g. deafness)	Individual	6
78 Primary caregiver(s) unemployment	Family/Caregiver	6
79 Social-communication problems	Individual	6
80 Air pollution	Society	6
81 Participation in the Free-Lunch Program	Individual	6
82 Low education level of primary caregiver(s)	Family/Caregiver	6
83 School composition (e.g. size/headcount, gender proportions, ethnicity proportions)	Society	4
84 Multi-generational families within the same home	Family/Caregiver	6
85 Migration from another country	Family/Caregiver	6
86 Visual impairment causing disability (e.g. blindness/partial sightedness)	Individual	5
=87 Serving in the military	Individual	3
=87 Missed ante-natal visits	Individual	5
89 English as an additional language	Society	6
90 Nitrous oxide use	Individual	2
91 Digital exclusion	Individual	4
92 Low socioeconomic status	Family/Caregiver	6
93 Remoteness of living	Society	6
94 Low education level of caregiver(s) (other than primary caregiver(s))	Family/Caregiver	6
95 Urbanicity	Society	5
96 Ethnicity	Individual	5
97 Climate change	Society	5
98 Belonging to a religious minority	Family/Caregiver	6
99 Belonging to a traveller community	Family/Caregiver	5
100 Religiosity	Individual	5
101 Religiosity of caregiver(s)	Family/Caregiver	6
102 Being a second generation immigrant	Individual	6
Key: == Tied positions _ = Risk factor has no ranking because it was unable to be rated by any respondents		

9.1.5 Appendix A.5 – Additional information available upon request

In the interest of brevity, some information has been omitted from this chapter, but can be provided upon request. This includes:

- 1) More detailed demographic tables separated out for Rounds 1 and 2. (A summary is presented in Table 2).
- 2) Reference list for developing the theoretical framework
- 3) 8 x tables of data, including Ns, underlying the life course heat maps for all risk factors

9.1.6 Appendix A.6 – Supplementary analysis: mapping Delphi risk factors for mental health problems to SAIL data dictionaries

9.1.6.1 *Background*

In order to explore whether the risk factors in the Delphi framework could be measured in routinely-collected data, I mapped all 287 risk factors to variables in the SAIL Databank using data dictionaries for all 18 databases to which I had access. These were mapped in order to understand which risk factors could theoretically be extracted from routine data and included in early identification models for detecting young people's mental health problems earlier.

9.1.6.2 *Brief methods*

For the mapping of risk factors, a spreadsheet was created showing if and how each risk factor was recorded in each of the 18 databases; the spreadsheet is too large to include here but the file is available upon request. During the mapping process, I found that there was a spectrum of measurability for the risk factors. This spectrum could be considered in terms of three categories: whether risk factors were 'directly measurable', 'derivable' or 'measurable by proxy' within each database (see Table 54 for definitions and examples of each type of measurability).

In the interest of time, the Timely team focused its efforts on 'directly measurable' and 'derivable' risk factors. Risk factors which could be 'measurable by proxy' are not discussed further here. I independently reviewed each database and recorded if it contained relevant risk factors, noting down the associated variable names and schema in which the variables were contained.

Table 54: How the measurement of risk factors was defined

Measurement type	Definition	Examples
Directly measurable	‘Directly measurable’ risk factors were defined as those which could be measured using the variable alone, without manipulation of the variable or taking into account information from other sources (including other variables). This means a variable exists in a database or databases which directly describes this risk factor.	‘Sex (biological)’ which is captured by the variables ‘GNDR_CD’, ‘PAT_SEX_CD’, ‘GENDER’ and ‘SEX’. ‘Participation in the Free-Lunch Program’ which is captured by the variables ‘FSM’ and ‘FSMELIGIBLE’. ‘Child protection record’ which is captured by the variable ‘child_protection_register’.
Derivable	‘Derivable’ risk factors were defined as those which could be measured by manipulation of information from one or more variables, or taking into account information from other sources.	‘Body Mass Index (BMI)’ can be calculated by using the variables height and weight. ‘Three or more presentations to emergency services within a year’ can be measured by summing distinct events from emergency service databases. ‘Anaemia’ can be measured by using the variable containing diagnostic codes in health databases and identifying codes consistent with a diagnosis of anaemia (e.g. Read codes, ICD-10 codes). (Of note, measuring risk factors such as this is likely to require discussion with a clinician(s) to identify relevant diagnostic codes, as opposed to work which can be carried out by the research team alone.)
Measurable by proxy	‘Measurable by proxy’ risk factors were those which could be estimated or inferred using a variable or a combination of variables. These measurements were an approximation or indicator of the risk factor in question, rather than being a direct or derived measure of it. There will be a greater degree of subjectivity in these measurements.	‘Low socioeconomic status family’ could be inferred using proxies such as employment status of parents/caregivers, lower super output area (LSOA) and index of multiple deprivation (IMD), and variables pertaining to eligibility for free school lunches. ‘Chronic (long lasting) infection (e.g. Lyme disease, periodontal disease)’ could be inferred through data on prescriptions for medication to fight infections. (Of note, it could also be derived as described above using diagnostic codes). ‘Household mental illness’ could be inferred from the antenatal health check databases using a variable which indicates that the mother has a health care plan for mental health problems. (Of note, this would only relate to the mother, not the whole ‘household’ and would not identify mothers who previously had care plans but no longer do, and it would also not cover mothers who go on to develop mental health problems later on in the child’s life (i.e. it only describes the child’s circumstances at birth)).

9.1.6.3 Findings

The findings of the mapping exercise are summarised in Table 55 and Table 56. The tables show which risk factors can be measured in each of the 18 SAIL databases, and the number of directly measurable and derivable risk factors, as well as the overall total number of factors measurable in each database. Table 55 presents risk factors from the main framework of the Delphi study (i.e. domains 1-7). Table 56 presents risk factors specifically relating to under-served populations (i.e. domain 8), with the aim of highlighting the extent to which it may be possible to measure risk factors identified as important to these particular populations.

With the aim of assessing the value of multi-agency data for predictive modelling, the databases are grouped into types (demographics, education, social care, general practice, and specialist or acute care), to illustrate the extent of coverage of variables in each database type. Of note, some risk factors were measurable in multiple databases; however, it is important to still use all of the databases because not every individual young person appears in every database (as highlighted in Table 22).

These tables are described as ‘qualitative tables’ because this risk factor mapping exercise led the team to conclude which factors we considered to be theoretically measurable based on SAIL metadata. Extracting these risk factors using code would allow us to conclude to what extent they are actually measurable. For example, some variables may have high missingness or be legacy variables no longer in use so do not actually contribute to risk factor measurement and model development. Of note, the scope of my thesis is limited to measuring the risk factors which meet my definition of ACEs, rather than measuring all risk factors in these tables.

In summary, of 287 risk factors of interest from domain 1-7 of the theoretical framework, 101 (35.19%) were theoretically measurable; this broke down into 48 (16.72%) which were directly measurable and 53 (18.47%) which were derivable (see Table 55). Of 101 risk factors of interest relating to under-served populations (i.e. domain 8 of the theoretical framework), 37 (36.63%) were measurable; this broke down into 26 (25.74%) which were directly measurable and 11 (10.89%) which were derivable (see Table 56).

Table 55: Qualitative table to show which risk factors we considered to be measurable in each database

Database Name	Directly Measurable Risk Factors	Total Directly Measurable	Derivable Risk Factors	Total Derivable	Total Measurable
Database Type: Demographics					
Welsh Demographic Service Dataset (WDSD)	Month of birth; Sex (biological)	2	Area deprivation (area code)	1	3
Annual District Birth Extract (ADBE)	Birth weight; Urbanicity	2	Primary caregiver(s) unemployment	1	3
Annual District Death Extract (ADDE)	N/A	0	Acute stress disorder (as a predictor of further mental health problems); Acute stress symptoms (anxiety, avoidance or depression - as a predictor of further mental health problems); Allergies (e.g. non-IgE-mediated food allergies, pollen allergies); Anaemia; Anxiety (as a predictor of further mental health problems); Asthma; Autoimmune disorders (e.g. rheumatoid arthritis); Chronic (long lasting) infection (e.g. Lyme disease, periodontal disease); Chronic (long lasting) gastric ill-health (e.g. inflammatory bowel disease); Chronic (long lasting) reflux or indigestion; Chronic inflammation; Congenital malformations; Diabetes; Eczema; Hypoxia (at birth); Increased panic attacks; Inflammatory diseases (e.g. Lyme disease); Intellectual disability; Irritable Bowel Syndrome (IBS); Long term antibiotic use; Low levels of B vitamins; Low	32	32

			levels of folate; Low levels of vitamin D; Low serum ferritin; Low serum vitamin D; Obesity/overweight; Prolonged duration of a physical health condition; Repeated infections; Severe health condition; Sleep disorder; Thyroid disease; Traumatic brain injury		

Database Type: Education

Pre-16 Education Attainment and Attendance – Wales (EDUW)	Ethnicity; Out-of-school discipline (e.g. suspension and expulsion); Participation in the Free-Lunch Program; School exclusions; Special Educational Needs (SEN)	5	Poor educational attainment; Poor school attendance; School-level deprivation (e.g. proportion eligible for free school meals)	3	8

Database Type: Social Care

Child In Need – Wales (CINW)	Being a looked after child (LAC); Child in need (CIN) status; Child protection record; Domestic violence; Ethnicity; Hearing impairment causing disability (e.g. deafness); Household alcohol abuse; Household drug abuse; Household mental illness; Involvement in criminal justice system; Neuro-developmental conditions (e.g. autism); Non-prescription drug use; Out-of-school discipline (e.g. suspension and expulsion); Physical disability; Primary caregiver(s) chronic (long lasting) illness; Primary caregiver(s) mental health problems; Problems with memory; Psychiatric history; School exclusions; Severe illness in family; Visual impairment causing disability (e.g. blindness/partial sightedness)	21	Emotional neglect; Failure to attend three or more planned health or social care appointments; Physical neglect	3	24

Children Receiving Care and Support (CRCS)	Being a looked after child (LAC); Child in need (CIN) status; Child protection record; Domestic violence; Emotional neglect; Emotional, psychological or verbal abuse; Experiencing financial abuse; Hearing impairment causing disability (e.g. deafness); Household alcohol abuse; Household drug abuse; Household mental illness; Involvement in criminal justice system; Neuro-developmental conditions (e.g. autism); Non-prescription drug use; Physical abuse; Physical disability; Physical neglect; Problems with memory; Primary caregiver(s) chronic (long lasting) illness; Primary caregiver(s) mental health problems; Psychiatric history; Severe illness in family; Sexual abuse; Visual impairment causing disability (e.g. blindness/partial sightedness)	24	Failure to attend three or more planned health or social care appointments	1	25
Looked After Children – Wales (LACW)	Being an unaccompanied asylum seeker; Being a looked after child (LAC)	2	Emotional neglect; Physical neglect	2	4
Database Type: General Practice					
Welsh Longitudinal General Practice (WLGP)	N/A	0	Acute stress disorder (as a predictor of further mental health problems); Acute stress symptoms (anxiety, avoidance or depression - as a predictor of further mental health problems); Allergies (e.g. non-IgE-mediated food allergies, pollen allergies); Anaemia; Anxiety (as a predictor of further mental health problems); Asthma; Autoimmune disorders (e.g. rheumatoid arthritis); Birth length; Chronic (long lasting)	34	34

			infection (e.g. Lyme disease, periodontal disease); Chronic (long lasting) gastric ill-health (e.g. inflammatory bowel disease); Chronic (long lasting) reflux or indigestion; Chronic inflammation; Congenital malformations; Diabetes; Disease history; Eczema; Hypoxia (at birth); Increased panic attacks; Inflammatory diseases (e.g. Lyme disease); Intellectual disability; Irritable Bowel Syndrome (IBS); Long term antibiotic use; Low levels of B vitamins; Low levels of folate; Low levels of vitamin D; Low serum ferritin; Low serum vitamin D; Obesity/overweight; Prolonged duration of a physical health condition; Repeated infections; Severe health condition; Sleep disorder; Thyroid disease; Traumatic brain injury		

Database Type: Specialist or Acute Healthcare

Critical Care Dataset (CCDS)	Urbanicity	1	Disease history; Repeat hospitalisation	2	3
Emergency Department Dataset (EDDS)	N/A	0	Acute stress disorder (as a predictor of further mental health problems); Acute stress symptoms (anxiety, avoidance or depression - as a predictor of further mental health problems); Allergies (e.g. non-IgE-mediated food allergies, pollen allergies); Anaemia; Anxiety (as a predictor of further mental health problems); Asthma; Autoimmune disorders (e.g. rheumatoid arthritis); Chronic (long lasting) infection (e.g. Lyme disease, periodontal disease); Chronic (long	33	33

			lasting) gastric ill-health (e.g. inflammatory bowel disease); Chronic (long lasting) reflux or indigestion; Chronic inflammation; Congenital malformations; Diabetes; Disease history; Eczema; Hypoxia (at birth); Increased panic attacks; Inflammatory diseases (e.g. Lyme disease); Intellectual disability; Irritable Bowel Syndrome (IBS); Long term antibiotic use; Low levels of B vitamins; Low levels of folate; Low levels of vitamin D; Low serum ferritin; Low serum vitamin D; Obesity/overweight; Prolonged duration of a physical health condition; Repeated infections; Severe health condition; Sleep disorder; Thyroid disease; Traumatic brain injury		
National Community Child Health (NCCH)	5-min Apgar score <7; Birth weight; Maternal smoking during pregnancy; Not breast fed; Premature birth	5	Birth length; Body mass Index (BMI); Disease history; Failure to attend three or more planned health or social care appointments; Global developmental delay; Obesity/overweight	6	11
NHS 111 Call Data (NHSO)	Ethnicity	1	Investigations by multiple services suggestive of suffering from medically unexplained symptoms; Three or more presentations to emergency services within a year	2	3
NHS Hospital Outpatients Dataset – Wales (OPDW)	N/A	0	Acute stress disorder (as a predictor of further mental health problems); Acute stress symptoms (anxiety, avoidance or depression - as a predictor of further mental health problems); Allergies (e.g. non-IgE-mediated food allergies, pollen allergies); Anaemia; Anxiety (as a predictor of further mental health problems); Asthma;	33	33

			Autoimmune disorders (e.g. rheumatoid arthritis); Chronic (long lasting) infection (e.g. Lyme disease, periodontal disease); Chronic (long lasting) gastric ill-health (e.g. inflammatory bowel disease); Chronic (long lasting) reflux or indigestion; Chronic inflammation; Congenital malformations; Diabetes; Disease history; Eczema; Hypoxia (at birth); Increased panic attacks; Inflammatory diseases (e.g. Lyme disease); Intellectual disability; Irritable Bowel Syndrome (IBS); Long term antibiotic use; Low levels of B vitamins; Low levels of folate; Low levels of vitamin D; Low serum ferritin; Low serum vitamin D; Obesity/overweight; Prolonged duration of a physical health condition; Repeated infections; Severe health condition; Sleep disorder; Thyroid disease; Traumatic brain injury		
Outpatient Referrals from Primary Care Dataset (OPRD)	Urbanicity	1	Disease history	1	2
Patient Episode Dataset – Wales (PEDW)	N/A	0	Acute stress disorder (as a predictor of further mental health problems); Acute stress symptoms (anxiety, avoidance or depression - as a predictor of further mental health problems); Allergies (e.g. non-IgE-mediated food allergies, pollen allergies); Anaemia; Anxiety (as a predictor of further mental health problems); Asthma; Autoimmune disorders (e.g. rheumatoid arthritis); Chronic (long lasting) infection (e.g.	33	33

			Lyme disease, periodontal disease); Chronic (long lasting) gastric ill-health (e.g. inflammatory bowel disease); Chronic (long lasting) reflux or indigestion; Chronic inflammation; Congenital malformations; Diabetes; Disease history; Eczema; Hypoxia (at birth); Increased panic attacks; Inflammatory diseases (e.g. Lyme disease); Intellectual disability; Irritable Bowel Syndrome (IBS); Long term antibiotic use; Low levels of B vitamins; Low levels of folate; Low levels of vitamin D; Low serum ferritin; Low serum vitamin D; Obesity/overweight; Prolonged duration of a physical health condition; Repeated infections; Severe health condition; Sleep disorder; Thyroid disease; Traumatic brain injury		
Substance Misuse Dataset (SMDS)	Being a young parent; Heavy alcohol use; Homelessness; Homelessness (young person has left home); Non-prescription drug use; Serving in the military; Unemployment of the individual	7	Disease history; Nitrous oxide use; Poor school attendance; Prescription drug abuse; Psychiatric history; Severe health condition	6	13
Wales Results Reporting Service (WRRS)	N/A	0	Acute stress disorder (as a predictor of further mental health problems); Acute stress symptoms (anxiety, avoidance or depression - as a predictor of further mental health problems); Allergies (e.g. non-IgE-mediated food allergies, pollen allergies); Anaemia; Anxiety (as a predictor of further mental health problems); Asthma; Autoimmune disorders (e.g. rheumatoid arthritis); Birth length; Chronic (long lasting)	36	36

			infection (e.g. Lyme disease, periodontal disease); Chronic (long lasting) gastric ill-health (e.g. inflammatory bowel disease); Chronic (long lasting) reflux or indigestion; Chronic inflammation; Congenital malformations; Diabetes; Disease history; Eczema; Hypoxia (at birth); Increased panic attacks; Inflammatory diseases (e.g. Lyme disease); Intellectual disability; Investigations by multiple services suggestive of suffering from medically unexplained symptoms; Irritable Bowel Syndrome (IBS); Long term antibiotic use; Low levels of B vitamins; Low levels of folate; Low levels of vitamin D; Low serum ferritin; Low serum vitamin D; Obesity/overweight; Prolonged duration of a physical health condition; Repeated infections; Severe health condition; Sleep disorder; Three or more presentations to emergency services within a year; Thyroid disease; Traumatic brain injury		
Maternity Indicators Dataset (MIDS)	5-min Apgar score <7; Age of parents at time of giving birth; Birth weight; Family history of psychiatric disorders; Maternal obesity/overweight during pregnancy; Maternal smoking during pregnancy; Month of birth; Not breast fed; Premature birth; Primary caregiver(s) mental health problems; Smoking status of primary caregiver(s)	11	Family history of severe mental illness (e.g. psychosis); Maternal depression during pregnancy; Household mental illness	3	14

Table 56: Qualitative table to show which risk factors specifically relating to under-served populations we considered to be measurable in each database

Database Name	Directly Measurable Risk Factors	Total Directly Measurable	Derivable Risk Factors	Total Derivable	Total Measurable
Database Type: Demographics					
Welsh Demographic Service Dataset (WDSD)	N/A	0	Area deprivation (area code)	1	1
Annual District Birth Extract (ADBE)	Urbanicity	1	Primary caregiver(s) unemployment	1	2
Annual District Death Extract (ADDE)	N/A	0	Intellectual disability	1	1
Database Type: Education					
Pre-16 Education Attainment and Attendance – Wales (EDUW)	Ethnicity; Out-of-school discipline (e.g. suspension and expulsion); Participation in the Free-Lunch Program; School exclusions; Special Educational Needs (SEN)	5	Poor school attendance; Poor educational attainment; School-level deprivation (e.g. proportion eligible for free school meals)	3	8
Database Type: Social Care					
Child In Need – Wales (CINW)	Being a looked after child (LAC); Child in need (CIN) status; Child protection record; Ethnicity; Hearing impairment causing disability (e.g. deafness); Household alcohol abuse; Household drug abuse; Household mental illness; Involvement in criminal justice system; Neuro-developmental conditions	16	Failure to attend three or more planned health or social care appointments	1	17

	(e.g. autism); Non-prescription drug use; Out-of-school discipline (e.g. suspension and expulsion); Physical disability; Primary caregiver(s) mental health problems; School exclusions; Visual impairment causing disability (e.g. blindness/partial sightedness)				
Children Receiving Care and Support (CRCS)	Being a looked after child (LAC); Child in need (CIN) status; Child protection record; Hearing impairment causing disability (e.g. deafness); Household alcohol abuse; Household drug abuse; Household mental illness; Involvement in criminal justice system; Neuro-developmental conditions (e.g. autism); Non-prescription drug use; Physical disability; Primary caregiver(s) mental health problems; Visual impairment causing disability (e.g. blindness/partial sightedness)	13	Failure to attend three or more planned health or social care appointments	1	14
Looked After Children – Wales (LACW)	Being an unaccompanied asylum seeker; Being a looked after child (LAC)	2	N/A	0	2
Database Type: General Practice					
Welsh Longitudinal General Practice (WLGP)	N/A	0	Intellectual disability	1	1
Database Type: Specialist or Acute Healthcare					
Critical Care Dataset (CCDS)	Urbanicity	1	N/A	0	1
Emergency Department	N/A	0	Intellectual disability	1	1

Dataset (EDDS)					
National Community Child Health (NCCH)	N/A	0	Failure to attend three or more planned health or social care appointments	1	1
NHS 111 Call Data (NHSO)	Ethnicity	1	N/A	0	1
NHS Hospital Outpatients Dataset – Wales (OPDW)	N/A	0	Intellectual disability	1	1
Outpatient Referrals from Primary Care Dataset (OPRD)	Urbanicity	1	N/A	0	1
Patient Episode Dataset – Wales (PEDW)	N/A	0	Intellectual disability	1	1
Substance Misuse Dataset (SMDS)	Being a young parent; Heavy alcohol use; Homelessness; Homelessness (young person has left home); Non-prescription drug use; Served in the military; Unemployment of the individual	7	Nitrous oxide use; Poor school attendance; Prescription drug abuse	3	10
Wales Results Reporting Service (WRRS)	N/A	0	Intellectual disability	1	1
Maternity Indicators Dataset (MIDS)	Primary caregiver(s) mental health problems	1	Household mental illness; Maternal depression during pregnancy	2	3

9.1.6.4 *Conclusions*

This mapping exercise illustrated that the risk factors considered to be important to predict young people's mental health problems cannot be found in one database alone, or database type. This supported the Timely team's hypothesis that in order to accurately predict young people's mental health problems, multi-agency data will be invaluable, rather than limiting risk factor measurement to single-agency data. Furthermore, it helped me to identify which databases would be particularly useful for measuring ACEs, a subset of the risk factors in the Delphi framework. Specifically, the social care and healthcare databases contained the majority of information relating to ACEs and this was confirmed when I separately conducted a specific ACE mapping exercise (as described in Chapter 5).

9.2 Appendix B – Chapter 5: Measurement of ACEs in a Database of Routinely-Collected, Linked Data

9.2.1 Appendix B.1 – Different databases within SAIL

Below (Table 57) is a description of each of the databases we accessed via the SAIL Databank, to give a better understanding of how the cohort for each database is created (e.g. who enters or leaves the database, for example when someone moves into Wales).

When reporting the approximate database sample size, these numbers are based on SAIL descriptions and reflect the database’s whole population, whereas for each database we were using a subset of young people only. As such, these numbers were lower for our cohort which reflects about a third of the whole possible population (1.1 million young people of a population of 3 million Welsh residents). A ‘♦’ is written after each sample to remind the reader of this. Project-specific figures are reported in the Results section of Chapter 5.

Table 57: Descriptions of databases

Database type	Abbreviation	Database name	Description of database
Demographics	WDSD	Welsh Demographic Service Dataset	This database is used as the baseline population for studies and consists of administrative information about individuals in Wales that use NHS services, such as address and practice registration history. The WDSD replaced the NHS Wales Administrative Register (NHSAR) in 2009. This database provides linkage from anonymous individuals to anonymous residences, thus enabling projects to group households of individuals. Data are drawn from GP practices via the Exeter System and are provided to SAIL by Digital Health and Care Wales. The data provision type is classed as an ‘administrative mandatory data return’. The database sample size is approximately 3 million♦ people, covering the Welsh population. However, for our study, we were using a subset of the sample including data from young people only. (Information taken from: https://data.ukserp.ac.uk/Asset/View/20)
	ADBE	Annual District Birth Extract	This database is an Office for National Statistics (ONS) register of all births in Wales. The data are provided by Digital Health and Care Wales. Data are collected from birth registrations and are classed as ‘registry data’. Typically, there are approximately 35,000 births per year in Wales which comprise this database. (Information taken from: https://data.ukserp.ac.uk/Asset/View/2)
	ADDE	Annual District Death Extract	This database is an Office for National Statistics (ONS) register of all deaths relating to Welsh residents, including individuals that died outside of Wales. The data are provided by Digital Health and Care Wales.

			Data are collected from death registrations and are classed as 'registry data'. Typically, there are approximately 32,000 deaths per year relating to Welsh residents which comprise this database. (Information taken from: https://data.ukserp.ac.uk/Asset/View/3)
Education	EDUW	Pre-16 Education Attainment and Attendance – Wales	This database includes records for all children registered at state schools in Wales or educated in settings other than school. It holds information on schools, examination results, attendance per year, exclusions per year, eligibility for free school meals, receipt of statement of special educational needs (SEN) and education other than at school (EOTAS). As well as individual-level data, it also contains school-level data. The data are provided by the Welsh Government. (Information taken from https://www.thelancet.com/cms/10.1016/S2215-0366(21)00367-9/attachment/fce3004d-88a7-4b14-ad0d-b6ff2c811ac6/mmc2.pdf, https://data.ukserp.ac.uk/Asset/View/35 and https://data.ukserp.ac.uk/Asset/View/1078)
Social Care	CINW	Child In Need – Wales	The CINW Census collected individual records on all children in need (CIN), including those looked after by a local authority, who had an open case with a local authority on the 31 March that had been open for the three months from 1 January to 31 March. The purpose of the census was to collect data that measured the characteristics and attributes of children in need who received social services from their local authorities, including children looked after by local authorities. The census focused particularly on data about the reason that children received help from social services departments, parental capacity, and on the health and education outcomes for each child. According to SAIL, the Children in Need Census and database (CINW) is superseded by Children Receiving Care and Support database (CRCS; described below). However, Welsh Government staff noted that these should not be treated as interchangeable because the legal definition of CIN changed between databases, meaning they are not focused on the same type of cohort. Collected variables are very similar but, due to legal definition changes, the cohort may differ. The data are provided by the Welsh Government. [These bullet points below are a duplication of points in the CRCS note section below so do not need to be read if you have read that section]. Of note: • These are censuses i.e. snapshots so people who have needs outside of the census window will be missed from the database. According to Lee and colleagues (2022): “A previous StatsWales release [20] estimates that the number of children included in the 2012 CIN census was 78% of the total number of children in need on 31st March 2012 recorded in another data collection [21], and so it is likely that approximately this proportion applies across all CIN and CRCS census years.” ...“There are also yes/no flags for looked after status, youth offending, child substance misuse, and if the child is on the child protection register. However, as previously discussed, if there is a change to one of these statuses outside the census return dates, the data are not recorded or retrospectively updated.”

-
- The linkage method relies on the use of Unique Pupil Numbers (UPN). As such, no records are currently available for children without a UPN, which includes most under age three (Lee et al., 2022).
 - In the following paper, see Table 1 and 2 on Pg. 4, which present the percentage of missing cases in CIN and CRCS. Also see Table 3 on Pg. 8 and Table 4 on Pg. 9 for health utilisation by CIN and CRCS population compared to baseline population: <https://iipds.org/article/view/1694/3387>
 - “One key feature of the Welsh censuses is that they only report on children who have received care or support for the whole period from January to March each year. The Welsh censuses collect individual records on all children in need, including those looked after by a local authority or those on the child protection register, who have an open case with a local authority on the 31st March that has been open continuously for the three months from 1st January to 31st March in the return year. They collect information on the characteristics and attributes of these children, including reasons for receipt of help from social services departments, parental capacity, and some indicators of health and health surveillance checks for each child.” (Lee et al., 2022)
 - Different definitions of ‘open case’: “For the CIN census, ‘open’ refers to cases in which the LA [local authority] took some sort of action during the collection period or, as of 31 March in a collection year, was planning to take action sometime in the future. Such cases may include young people aged 18 or over who are still receiving care and accommodation or post-care support (leaving care services) from children’s services and unborn children if they are felt to be ‘at risk’. Other included cases are children supported via adult teams, children receiving nursery provision funded solely by children’s social services, children receiving contracted-out provision from voluntary organisations that are funded by children’s social services, children who are privately fostered, and also children who are waiting for a service at the census date. Within the CRCS census, however, ‘open’ only refers to cases in which there is an active care and support plan that has been provided following an assessment and eligibility test undertaken by social services. Children are only eligible for a care and support plan when their needs for care and support can and can only be met by the local authority providing, arranging, or making direct payments for care and support. Therefore, unlike the CIN census, the CRCS census does not include details on children waiting for a service or an assessment, unborn children, or any individual over the age of 18. However, the CRCS census will capture children who have a support plan if they are providing care to someone else.” (Lee et al., 2022)
 - Lee and colleagues (2022) found “CRCS data held within the SAIL Databank comprises 25,972 records, 81% of the total number of records reported by the Welsh Government. The CIN data contains 108,449 records, 79% of the Welsh Government’s records for this data collection...There is a slight overlap with 10,552 children present in both the CIN and CRCS censuses, with both combined datasets containing information relating to 49,350 unique children...Health service use of children in need, and children receiving care and support, was roughly equal to that of the non-CIN/CRCS population, except GP visits, where children in need had fewer consultations, and children receiving care and support had more consultations than the comparison population.”
-

-
- Measuring mental health in CIN and CRCS: “Only children aged over 10 are eligible to be flagged for a mental health problem in the CIN and CRCS censuses. This field includes problems diagnosed by a medical practitioner, children receiving CAMHS, or children waiting for services. Children are also recorded if they report experiencing mental health problems without a concrete diagnosis. 7.5% of entries in CIN report some mental health problem, increasing very slightly to 8.4% of entries in CRCS.” (Lee et al., 2022)
 - Lack of date information and case information for longitudinal research: “Very little case-specific social care services information is available in CIN or CRCS, with no recording of individual episodes within cases (e.g., if a case is closed and shortly after this closure a second case is opened). They also do not record any dates relating to actions taken, except in CRCS, where the date of entry to the child protection register is recorded. Due to the lack of critical dates within both censuses, they have limitations for stand-alone longitudinal research. For children looked after, other social care and family justice datasets provide fuller information so are more useful for longitudinal research.”...“Between 2009/10 and 2015/16, the Children in Need return provides no granular information about the entry to the child protection register (CPR) – such as the start date or reason — and instead relies on a yes/no indicator. One change brought about by the Social Services and Well Being Act (Wales) 2014 was that the CRCS census records more detailed information about the date a child was added to the CPR and the reason for this addition.”...“First and foremost, these datasets are administrative datasets collected to understand service utilisation at a country and county level and inform future direction and funding for service provision. While limitations of these datasets do impact their utility as research datasets, they are still able to perform their original intended function.”...“Despite these limitations, the available data, when linked to other data sets, enable researchers to study predictors and outcomes of social care service use.” (Lee et al., 2022)
 - Issues of coding practices: “Both censuses use ‘need for care and support’ as a broad indicator for the reason that a child is present in the dataset. However, a child might be eligible for care and support for a combination of reasons — guidance notes [23] for the CRCS and CIN census indicate that the return should use the primary reason for social services involvement. However, these can be arbitrary judgements and are inconsistently applied in some years and local authorities [27, 28]. For example, one local authority sees a drop in need due to abuse and neglect from 85% to 15% in the space of one year (from the 2011 to 2012 return). In the 2011/2012 return, the same local authority reports a sizeable increase in need due to family dysfunction from 2% to 67%. This holds for the 2013 return but need code usage reverted to its previous state in 2014. It is also possible for the need code to differ between census return years for the same child, between the CIN and CRCS returns, and the Looked After Children census return for the same year. For a full breakdown of the need codes and their descriptions, please see Appendix 3.”...“The category of need code variable should also be used with caution. It is a subjective judgement made by the social worker who is completing the census return for the child, and we see that need code usage is inconsistent across years and local authorities. Studies that intend to classify children via this variable should consider this field to be of unknown
-

accuracy. We would recommend that they consider deriving some other measure via data fields that are likely to have higher accuracy, e.g. child disability factors, parental capacity factors.”

- Issues with definition/eligibility of specific variables: “The youth offending flag indicates that a plan is in place or in development with the Youth Offending Team. It is important to note that this flag can only be used for children over the age of 10 – the age of criminal responsibility in Wales – on 31st March in a given return year. The same age constraint also applies to the flag for children with substance misuse problems.” (Lee et al., 2022)
- “The LSOA present in the CIN and CRCS datasets is not necessarily the LSOA that a child resided in when interacting with social services and is more likely to be the LSOA of their most recent residence. For children looked after in foster or residential care this may be the address of their placement. This is because LSOAs are assigned based on the postcode that is given to the secure third party who carry out the matching process, and any postcode retrieved via the UPN linkage method is a child’s most recently reported postcode in the PLASC (Pupil Level Annual School Census). Our suggested mitigation strategy for researchers interested in LSOA characteristics is to link the census data to the Welsh Demographic Survey Dataset (WDS) and search for the corresponding LSOA at the time of the child’s first census appearance.” (Lee et al., 2022)

(Information taken from <https://data.ukserp.ac.uk/Asset/View/1101> and <https://ijpds.org/article/view/1694/3387>) (Other information on legal definitions and element level data etc can be found here: <https://aleex.notion.site/Dataset-Guidance-Notes-955bf6dc17074ca5b56aee6bfc958dc9>; published paper can be found here: <https://ijpds.org/article/view/1694/3387>)

CRCS	Children Receiving Care and Support	Following the commencement of the Social Services and Well-being (Wales) Act in April 2016, the Children In Need Census (and corresponding database, CINW) has been discontinued and replaced by the Children Receiving Care and Support Census (and corresponding database, CRCS). The Children Receiving Care and Support Census is based on the definition of eligible children who have care and support, i.e. children (under the age of 18) who have a care and support plan. The data sample size for CRCS is approximately 16,000. The data are provided by the Welsh Government. [These bullet points below are a duplication of points in the CINW note section above so do not need to be read if you have read that section]. Of note: • These are censuses i.e. snapshots so people who have needs outside of the census window will be missed from the database. According to Lee and colleagues (2022): “A previous StatsWales release [20] estimates that the number of children included in the 2012 CIN census was 78% of the total number of children in need on 31st March 2012 recorded in another data collection [21], and so it is likely that approximately this proportion applies across all CIN and CRCS census years.”...“There are also yes/no flags for looked after status, youth offending, child substance misuse, and if the child is on the child protection register. However, as previously discussed, if there is a change to one of these statuses outside the census return dates, the data are not recorded or retrospectively updated.”

-
- The linkage method relies on the use of Unique Pupil Numbers (UPN). As such, no records are currently available for children without a UPN, which includes most under age three (Lee et al., 2022).
 - In the following paper, see Table 1 and 2 on Pg. 4, which present the percentage of missing cases in CIN and CRCS. Also see Table 3 on Pg. 8 and Table 4 on Pg. 9 for health utilisation by CIN and CRCS population compared to baseline population: <https://iipds.org/article/view/1694/3387>
 - “One key feature of the Welsh censuses is that they only report on children who have received care or support for the whole period from January to March each year. The Welsh censuses collect individual records on all children in need, including those looked after by a local authority or those on the child protection register, who have an open case with a local authority on the 31st March that has been open continuously for the three months from 1st January to 31st March in the return year. They collect information on the characteristics and attributes of these children, including reasons for receipt of help from social services departments, parental capacity, and some indicators of health and health surveillance checks for each child.” (Lee et al., 2022)
 - Different definitions of ‘open case’: “For the CIN census, ‘open’ refers to cases in which the LA took some sort of action during the collection period or, as of 31 March in a collection year, was planning to take action sometime in the future¹. Such cases may include young people aged 18 or over who are still receiving care and accommodation or post-care support (leaving care services) from children’s services and unborn children if they are felt to be ‘at risk’. Other included cases are children supported via adult teams, children receiving nursery provision funded solely by children’s social services, children receiving contracted-out provision from voluntary organisations that are funded by children’s social services, children who are privately fostered, and also children who are waiting for a service at the census date. Within the CRCS census, however, ‘open’ only refers to cases in which there is an active care and support plan that has been provided following an assessment and eligibility test undertaken by social services. Children are only eligible for a care and support plan when their needs for care and support can and can only be met by the local authority providing, arranging, or making direct payments for care and support. Therefore, unlike the CIN census, the CRCS census does not include details on children waiting for a service or an assessment, unborn children, or any individual over the age of 18. However, the CRCS census will capture children who have a support plan if they are providing care to someone else.” (Lee et al., 2022)
 - Lee and colleagues (2022) found “CRCS data held within the SAIL Databank comprises 25,972 records, 81% of the total number of records reported by the Welsh Government. The CIN data contains 108,449 records, 79% of the Welsh Government’s records for this data collection...There is a slight overlap with 10,552 children present in both the CIN and CRCS censuses, with both combined datasets containing information relating to 49,350 unique children...Health service use of children in need, and children receiving care and support, was roughly equal to that of the non-CIN/CRCS population, except GP visits, where children in need had fewer consultations, and children receiving care and support had more consultations than the comparison population.”
-

-
- Measuring mental health in CIN and CRCS: “Only children aged over 10 are eligible to be flagged for a mental health problem in the CIN and CRCS censuses. This field includes problems diagnosed by a medical practitioner, children receiving CAMHS, or children waiting for services. Children are also recorded if they report experiencing mental health problems without a concrete diagnosis. 7.5% of entries in CIN report some mental health problem, increasing very slightly to 8.4% of entries in CRCS.” (Lee et al., 2022)
 - Lack of date information and case information for longitudinal research: “Very little case-specific social care services information is available in CIN or CRCS, with no recording of individual episodes within cases (e.g., if a case is closed and shortly after this closure a second case is opened). They also do not record any dates relating to actions taken, except in CRCS, where the date of entry to the child protection register is recorded. Due to the lack of critical dates within both censuses, they have limitations for stand-alone longitudinal research. For children looked after, other social care and family justice datasets provide fuller information so are more useful for longitudinal research.”...“Between 2009/10 and 2015/16, the Children in Need return provides no granular information about the entry to the child protection register (CPR) — such as the start date or reason — and instead relies on a yes/no indicator. One change brought about by the Social Services and Well Being Act (Wales) 2014 was that the CRCS census records more detailed information about the date a child was added to the CPR and the reason for this addition.”...“First and foremost, these datasets are administrative datasets collected to understand service utilisation at a country and county level and inform future direction and funding for service provision. While limitations of these datasets do impact their utility as research datasets, they are still able to perform their original intended function.”...“Despite these limitations, the available data, when linked to other data sets, enable researchers to study predictors and outcomes of social care service use.” (Lee et al., 2022)
 - Issues of coding practices: “Both censuses use ‘need for care and support’ as a broad indicator for the reason that a child is present in the dataset. However, a child might be eligible for care and support for a combination of reasons — guidance notes [23] for the CRCS and CIN census indicate that the return should use the primary reason for social services involvement. However, these can be arbitrary judgements and are inconsistently applied in some years and local authorities [27, 28]. For example, one local authority sees a drop in need due to abuse and neglect from 85% to 15% in the space of one year (from the 2011 to 2012 return). In the 2011/2012 return, the same local authority reports a sizeable increase in need due to family dysfunction from 2% to 67%. This holds for the 2013 return but need code usage reverted to its previous state in 2014. It is also possible for the need code to differ between census return years for the same child, between the CIN and CRCS returns, and the Looked After Children census return for the same year. For a full breakdown of the need codes and their descriptions, please see Appendix 3.”...“The category of need code variable should also be used with caution. It is a subjective judgement made by the social worker who is completing the census return for the child, and we see that need code usage is inconsistent across years and local authorities. Studies that intend to classify children via this variable should consider this field to be of unknown
-

accuracy. We would recommend that they consider deriving some other measure via data fields that are likely to have higher accuracy, e.g. child disability factors, parental capacity factors.”

- Issues with definition/eligibility of specific variables: “The youth offending flag indicates that a plan is in place or in development with the Youth Offending Team. It is important to note that this flag can only be used for children over the age of 10 – the age of criminal responsibility in Wales – on 31st March in a given return year. The same age constraint also applies to the flag for children with substance misuse problems.” (Lee et al., 2022)
- “The LSOA present in the CIN and CRCS datasets is not necessarily the LSOA that a child resided in when interacting with social services and is more likely to be the LSOA of their most recent residence. For children looked after in foster or residential care this may be the address of their placement. This is because LSOAs are assigned based on the postcode that is given to the secure third party who carry out the matching process, and any postcode retrieved via the UPN linkage method is a child’s most recently reported postcode in the PLASC (Pupil Level Annual School Census). Our suggested mitigation strategy for researchers interested in LSOA characteristics is to link the census data to the Welsh Demographic Survey Dataset (WDS) and search for the corresponding LSOA at the time of the child’s first census appearance.” (Lee et al., 2022)

(Information taken from: <https://data.ukserp.ac.uk/Asset/View/33> and <https://ijpds.org/article/view/1694/3387>) (Other information on legal definitions and element level data etc can be found here: <https://aleex.notion.site/Dataset-Guidance-Notes-955bf6dc17074ca5b56aee6bfc958dc9>; published paper can be found here: <https://ijpds.org/article/view/1694/3387>)

LACW	Looked After Children – Wales	This database provides information on young people on care orders and in placements, as well as covering adoption from care, and young people leaving care. The data are provided by the Welsh Government. Of note: • Allnatt and colleagues (2022; https://ijpds.org/article/view/1752/) provide a collection definition of ‘looked after’ in Appendix 1, Pg. 9). • How the database comes about and defining the cohort: “Information about children in care is routinely collected by local authorities and submitted to the Welsh Government annually in the form of the Children Looked After Census, which was previously referred to as the SSDA903 Return. In Wales, children in State care (referred to in this paper as ‘children looked after’) are ‘looked after’ by a local authority under the Children Act (1989) or the Social Services and Well-being (Wales) Act (2014)¹. Under the latter Act, specifically Section 76, children and young people can become ‘looked after’ through a voluntary arrangement referred to as ‘voluntary accommodation’. This arrangement is made with parental consent and is not mandated by the courts. Parents retain legal rights and the right to withdraw consent for accommodation at any time. Section 77 of the 2014 Act also requires local authorities to accommodate children who are removed or kept away from home under Part 5 of the Children Act 1989, i.e. those children who are in police protection, detention, or on remand. The alternative route into the care system

is through a court order. In circumstances where there is serious risk of harm to a child or young person local authorities can apply to the court for an order that gives a local authority parental responsibility of the child. In Wales, like England, court orders are applied for and granted under Section 31 of the Children Act (1989). Courts have the powers to issue emergency protection orders, interim care orders or a full care order. A full care order can be mandated by the court where local authorities share parental responsibility with birth parents but have the power to decide if contact with parents is in the best interest of the child and, if it is, how much contact. Children and young people on a care order may be placed with unrelated foster carers and some may be with kinship foster carers or birth parents. Where they are placed with birth parents, this will typically be as part of a process of reunification for children who have previously been removed from home.”...”The Children Looked After data collection includes a broader group of children than just those looked after under s.76 and s.77 of the 2014 Act and Part IV of the 1989 Act. It also includes children who receive short breaks of a continuous period of more than 24 hours as part of a Part 6 care and support plan, children placed for adoption, children who are placed with prospective adoptive parents, and children aged 16 or 17 and in transitional settings in preparation for leaving care, among others. Prescriptive guidance sets out the groups of children who are and are not eligible to be included in the census, and an exhaustive list is available in Appendix 1.” (Allnatt et al., 2022)

- Database structure: “The Children Looked After dataset available inside the SAIL Databank covers 1st April 2001 – 31st March 2021 and will continue to be updated each year, offering a minimum of two decades of individual-level data about children who have been looked after at any point during this period. The data available inside SAIL consists of approximately 310,550 recorded episodes, reflecting data for 37,775 unique children. This data collection has an ‘episodic’ structure, with the period during which a child is looked after by the local authority being broken down into ‘episodes’ of care. A new episode begins every time a child starts to be looked after; there is a change in the child’s legal status; or the child’s placement changes. Episodes are recorded in consecutive date order. Episode completion information is only populated if an episode ends within a collection year (1st April – 31st March). If the episode is still open on 31st March in a census year, then the end date and reason for the end of the episode are left blank, and the following year’s record starts with the same episode details. In cases where a single open episode continues unchanged from year-to-year a record is still submitted every year for that child.” (Allnatt et al., 2022). Of note, SAIL Databank metadata states the coverage dates as 21st June 1999 – 31st March 2018 instead of those above.

(Information taken from: <https://data.ukserp.ac.uk/Asset/View/37>) (Other information on legal definitions and element level data etc can be found here: <https://aleex.notion.site/Dataset-Guidance-Notes-955bf6dc17074ca5b56aee6bfc958dc9>; published paper can be found here: <https://ijpds.org/article/view/1752/>)

Healthcare (General Practice)	WLGP	Welsh Longitudinal General Practice	This database consists of data from GP practices’ clinical information systems, which are used to maintain an electronic health record for each patient, capturing the signs, symptoms, test results, diagnoses,

			prescribed treatment, referrals for specialist treatment and social aspects relating to the patient's home environment. The data are provided by Welsh General Practices that have signed up to SAIL (approx. 80% of GP practices, according to Lee and colleagues (2022)). The majority of the data are entered by the clinician during a patient consultation; tests results are electronically transferred from secondary care systems. The data provision type is classed as 'clinical system data'. Typically, the data sample size is approximately 5,000, but ranges from 1,000 to 30,000, depending on the particular contributing general practice. Of note: • There are no standard rules for recording data within primary care clinical information systems. Therefore, each individual clinician can record information in their own way. The majority use Read Code terminology, however, sometimes this is applied behind the scenes by the clinical system and sometimes local codes are used. Read Codes are not as precise as ICD-10 or OPCS codes. • Coding standards have been agreed on for conditions monitored by the Quality Outcomes Framework (QOF) returns. Since the implementation of QOF, these conditions have been coded in a more consistent way. • Time coverage varies between each practice. (Information taken from: https://data.ukserp.ac.uk/Asset/View/17)
Community Healthcare	NCCH	National Community Child Health	This database includes birth registration and monitoring of child health examinations and immunisations. It brings together data from local Child Health System databases which are held by NHS Trusts and used by them to administer child immunisation and health surveillance programmes. The database contains all children born, resident or treated in Wales and born after 1987. The data provision type is classed as an 'administrative mandatory data return'. The data are provided by Digital Health and Care Wales. Typically, there are approximately 35,000 births and approximately 500,000 vaccinations per year in Wales which comprise this database. (Information taken from: https://data.ukserp.ac.uk/Asset/View/10)
	MIDS	Maternity Indicators Dataset	This database provides data relating to the woman at initial assessment and to mother and baby (or babies) for all births. The data are provided by Digital Health and Care Wales. Of note: • This relates to initial assessment and birth activity undertaken in Wales only. • Each Health Board must make available data in relation to the initial assessments and/or birth events which they managed. ○ For example, if they only carried out the initial assessment, the Health Board would only be required to provide the initial assessment data. SAIL notes this is detailed in the technical specification (see 'return submission details').

		○ Where the initial assessment and birth events take place in different Health Boards, data will be linked nationally by the NHS Wales Informatics Service. • Velindre NHS Trust are excluded from this requirement, as they do not provide any maternity services. • Monthly activity data must include only initial assessment and birth activity that took place in the previous month. (Information taken from: https://data.ukserp.ac.uk/Asset/View/23)
OPDW	NHS Hospital Outpatients Dataset – Wales	This database provides attendance information for all NHS Wales hospital scheduled outpatient appointments, including those where the patient did not attend. The data are provided by Digital Health and Care Wales. The data are collected and coded at each hospital. Administrative information such as specialty of care, appointment date and attendance status are collected from the central Patient Administrative System (PAS). The data provision type is classed as an ‘administrative mandatory data return’. Typically, there are approximately 4,500,000♦ appointments per year in Wales which comprise this database. (Information taken from: https://data.ukserp.ac.uk/Asset/View/14)
OPRD	Outpatient Referrals from Primary Care Dataset	This database provides data on the complete referral pathway to secondary care, including all clinical referrals received from General Practitioners, General Dental Practitioners, Community Dental Services, A&E Departments, self-referrals, walk-ins or emergency patients accompanied by a GP letter, and Consultant-to-Consultant referrals. The data are provided by Digital Health and Care Wales. The data provision type is classed as an ‘administrative mandatory data return’ and the return is submitted monthly by Local Health Boards. Typically, there are approximately 1,000,000♦ records per year in Wales which comprise this database. (Information taken from: https://data.ukserp.ac.uk/Asset/View/12)
WRRS	Wales Results Reporting Service	This database gives clinicians blood results for patients, regardless of where they had their blood taken. As such, rather than travelling to have blood tests, patients can go to mobile units, or local centres, and clinicians can see the results. The data are provided by Digital Health and Care Wales. (Information taken from: https://data.ukserp.ac.uk/Asset/View/1095)
SMDS	Substance Misuse Dataset	This database provides data relating to all clients, both young people and adults, presenting for substance misuse treatment in Wales. Welsh providers delivering substance misuse treatment and who are in receipt of Welsh Government substance misuse revenue funding are required to submit the data. The data are provided by Digital Health and Care Wales. Of note: • Treatment Outcomes Profiles are only required to be completed for adults (age 16+) in receipt of structured treatments. (Information taken from: https://data.ukserp.ac.uk/Asset/View/24)

NHSO	NHS 111 Call Data	This database provides statistics from the ambulance service and NHS 111 call centres. The data are provided by Welsh Ambulance Service NHS Trust. (Information taken from: https://data.ukserp.ac.uk/Asset/View/1062)
Acute Healthcare	PEDW	Patient Episode Dataset – Wales This database is the NHS Wales hospital admissions (both inpatient and daycases) database and comprises attendance and clinical information for all hospital admissions, including diagnoses and operations performed. Clinical information in PEDW is coded using ICD-10 (World Health Organisation, 2016), an international standard for diagnostic classification of diseases and other health conditions. The data are at an individual person-level, and also include spell and episode-level data. The data are provided by Digital Health and Care Wales. The data are collected and coded at each hospital. Administrative information such as specialty of care and admission and dates are collected from the central Patient Administrative System (PAS); after the patient is discharged, hand-written patient notes are transcribed by a clinical coder into medical coding terminology (i.e. ICD-10 and OPCS). The data provision type is classed as an ‘administrative mandatory data return’. Typically, there are approximately 950,000 hospital admissions per year in Wales which comprise this database. According to SAIL, the PEDW data are of interest to public health services as it can provide information on both health service utilisation and also the incidence and prevalence of disease. However, they note that since PEDW was created to track hospital activity from the point of view of payments for services, rather than epidemiological analysis, the use of PEDW for public health work is not straightforward. SAIL give the following examples of complexity: • When looking at diagnosis or procedures, the number will vary depending on whether you only look at the primary diagnosis/procedure field or if the secondary fields are also included. • There are a number of different things that can be counted in PEDW e.g. individual episodes of care, admissions, discharges, periods of continuous care (group of episodes), patients or procedures. • Coding practices vary. In particular, coding practices for recording secondary diagnoses are likely to vary for different hospitals. This inconsistency of practice makes regional variations more difficult to interpret. (Of note, the validation process led by the Corporate Health Improvement Programme and implemented by NWIS is aiming to address some of these inconsistencies). SAIL notes that due to the complexity and pitfalls of PEDW, it is recommended that any PEDW requests for public health purposes are discussed with a member of the SAIL team, after which SAIL will seek advice from NWIS if required. (Information taken from: https://data.ukserp.ac.uk/Asset/View/15 and https://www.thelancet.com/cms/10.1016/S2215-0366(21)00367-9/attachment/fce3004d-88a7-4b14-ad0d-b6ff2c811ac6/mmc2.pdf)

EDDS	Emergency Department Dataset	This database consists of administrative and clinical information for all NHS Wales Accident and Emergency department attendances; it also includes the All Wales Injury Surveillance Systems (AWISS) database. The data are provided by Digital Health and Care Wales. The data are collected and coded at each hospital. The data provision type is classed as an 'administrative mandatory data return'. Typically, there are approximately 750,000♦ attendances per year in Wales which comprise this database. Of note: • Data recording practices may vary, especially in some of the minor A&E and Minor Injury Units. SAIL highlights that this could account for some local differences. (Information taken from: https://data.ukserp.ac.uk/Asset/View/13)
CCDS	Critical Care Dataset	This database is a nation-wide critical care database used to monitor quality of service and to drive improvements and policy development. The data are provided by Digital Health and Care Wales. Data are collected and coded at each hospital; administrative information such as admission and discharge date and times are collected from the central Patient Administrative System (PAS). The data provision type is classed as an 'administrative mandatory data return'. Typically, there are approximately 9,000♦ admissions per year in Wales which comprise this database. According to SAIL, the CCDS is a good supplementary database alongside the hospital inpatient database PEDW (described above), covering the period of critical care the patient received, including intensity of care (e.g. bed levels, organ support), treatment specialty, and outcome. (Information taken from: https://data.ukserp.ac.uk/Asset/View/8)

9.2.2 Appendix B.2 – Writing code lists to measure ACEs in SAIL

Table 58: ACEs mapped to Delphi risk factors and proposed SAIL variables

Overarching ACE concept	ACE sub-concept	Any related Delphi risk factor(s)	Corresponding SAIL variable(s) [SAIL schema name]	Comments
Abuse and Neglect	Sexual Abuse	Sexual abuse	CPR_SEXUAL_ABUSE [SAILW1336V.KP_CRCS]	
		Child protection record	- CHILD_PROTECTION_REGISTER [SAILW1336V.KP_CINW] - RECENT_REFERRAL_CHILD_PREVIOUSLY_ON_CPR [SAILW1336V.KP_CINW] - CHILD_PROTECTION_REGISTER [SAILW1336V.KP_CRCS] - ON_PROTECTION_REGISTER [SAILW1336V.KP_NCCH_HC]	
		Being a looked after child (LAC)	- Simply being present in LACW database is indicator of LAC status - LOOKED_AFTER_CHILD [SAILW1336V.KP_CINW] - RECENT_REFERRAL_CHILD_PREVIOUSLY_LAC [SAILW1336V.KP_CINW] - LOOKED_AFTER_CHILD [SAILW1336V.KP_CRCS] - EPISODE_NUMBER [SAILW1336V.KP_LACW] - CATEGORY_OF_NEED_CODE [SAILW1336V.KP_LACW] - LOOKED_AFTER [SAILW1336V.KP_NCCH_HC] - LEGAL_STATUS_CODE [SAILW1336V.KP_LACW]	
		Child in need (CIN) status	- Simply being present in CINW database is indicator of CIN status - CATEGORY_OF_NEED_CODE [SAILW1336V.KP_CINW] - CATEGORY_OF_NEED_CODE [SAILW1336V.KP_CRCS] - CATEGORY_OF_NEED_CODE [SAILW1336V.KP_LACW] - LOOKED_AFTER	
	Physical Abuse	Physical abuse	- CPR_PHYSICAL_ABUSE [SAILW1336V.KP_CRCS] - FGM_EVIDENCE [SAILW1336V.KP_NCCH_HC]	
		Domestic violence	- RECENT_REFERRAL_PARENTAL_DOMESTIC_ABUSE [SAILW1336V.KP_CINW] - DOMESTIC_VIOLENCE [SAILW1336V.KP_NCCH_HC] - PARENTING_CAPACITY_DOMESTIC_ABUSE [SAILW1336V.KP_CRCS] - PARENTING_CAPACITY_DOMESTIC_ABUSE [SAILW1336V.KP_CINW]	Is also counted in household adversity (domestic violence)

	Child protection record	• CHILD_PROTECTION_REGISTER [SAILW1336V.KP_CINW] • RECENT_REFERRAL_CHILD_PREVIOUSLY_ON_CPR [SAILW1336V.KP_CINW] • CHILD_PROTECTION_REGISTER [SAILW1336V.KP_CRCS] • ON_PROTECTION_REGISTER [SAILW1336V.KP_NCCH_HC]
	Being a looked after child (LAC)	• Simply being present in LACW database is indicator of LAC status • LOOKED_AFTER_CHILD [SAILW1336V.KP_CINW] • RECENT_REFERRAL_CHILD_PREVIOUSLY_LAC [SAILW1336V.KP_CINW] • LOOKED_AFTER_CHILD [SAILW1336V.KP_CRCS] • EPISODE_NUMBER [SAILW1336V.KP_LACW] • CATEGORY_OF_NEED_CODE [SAILW1336V.KP_LACW] • LOOKED_AFTER [SAILW1336V.KP_NCCH_HC] • LEGAL_STATUS_CODE [SAILW1336V.KP_LACW]
	Child in need (CIN) status	• Simply being present in CINW database is indicator of CIN status • CATEGORY_OF_NEED_CODE [SAILW1336V.KP_CINW] • CATEGORY_OF_NEED_CODE [SAILW1336V.KP_CRCS] • CATEGORY_OF_NEED_CODE [SAILW1336V.KP_LACW] • LOOKED_AFTER
Emotional or Verbal Abuse	Emotional, psychological or verbal abuse	• CPR_EMOTIONAL_ABUSE [SAILW1336V.KP_CRCS]
	Frequent fear of family member	• _
	Child protection record	• CHILD_PROTECTION_REGISTER [SAILW1336V.KP_CINW] • RECENT_REFERRAL_CHILD_PREVIOUSLY_ON_CPR [SAILW1336V.KP_CINW] • CHILD_PROTECTION_REGISTER [SAILW1336V.KP_CRCS] • ON_PROTECTION_REGISTER [SAILW1336V.KP_NCCH_HC]

	Being a looked after child (LAC)	• Simply being present in LACW database is indicator of LAC status • LOOKED_AFTER_CHILD [SAILW1336V.KP_CINW] • RECENT_REFERRAL_CHILD_PREVIOUSLY_LAC [SAILW1336V.KP_CINW] • LOOKED_AFTER_CHILD [SAILW1336V.KP_CRCS] • EPISODE_NUMBER [SAILW1336V.KP_LACW] • CATEGORY_OF_NEED_CODE [SAILW1336V.KP_LACW] • LOOKED_AFTER [SAILW1336V.KP_NCCH_HC] • LEGAL_STATUS_CODE [SAILW1336V.KP_LACW]	
	Child in need (CIN) status	• Simply being present in CINW database is indicator of CIN status • CATEGORY_OF_NEED_CODE [SAILW1336V.KP_CINW] • CATEGORY_OF_NEED_CODE [SAILW1336V.KP_CRCS] • CATEGORY_OF_NEED_CODE [SAILW1336V.KP_LACW] • LOOKED_AFTER	
Neglect	Being a looked after child (LAC)	• Simply being present in LACW database is indicator of LAC status • LOOKED_AFTER_CHILD [SAILW1336V.KP_CINW] • RECENT_REFERRAL_CHILD_PREVIOUSLY_LAC [SAILW1336V.KP_CINW] • LOOKED_AFTER_CHILD [SAILW1336V.KP_CRCS] • EPISODE_NUMBER [SAILW1336V.KP_LACW] • CATEGORY_OF_NEED_CODE [SAILW1336V.KP_LACW] • LOOKED_AFTER [SAILW1336V.KP_NCCH_HC] • LEGAL_STATUS_CODE [SAILW1336V.KP_LACW]	
	Child in need (CIN) status	• Simply being present in CINW database is indicator of CIN status • CATEGORY_OF_NEED_CODE [SAILW1336V.KP_CINW] • CATEGORY_OF_NEED_CODE [SAILW1336V.KP_CRCS] • CATEGORY_OF_NEED_CODE [SAILW1336V.KP_LACW] • LOOKED_AFTER	Of note, can be CIN for other reasons e.g. disability; will address using 'Category of Need' code in SAIL.
	Emotional neglect	• CPR_NEGLECT [SAILW1336V.KP_CRCS] • CATEGORY_OF_NEED_CODE [SAILW1336V.KP_CRCS] • CATEGORY_OF_NEED_CODE [SAILW1336V.KP_CINW] • CATEGORY_OF_NEED_CODE [SAILW1336V.KP_LACW] • REASON_EPISODE_STARTED_CODE [SAILW1336V.KP_LACW]	

		Physical neglect	• CPR_NEGLECT [SAILW1336V.KP_CRCS] • HEALTH_IMMUNISATIONS [SAILW1336V.KP_CINW] • HEALTH_IMMUNISATIONS [SAILW1336V.KP_CRCS] • CHILD_HEALTH_SURVEILLANCE_CHECKS [SAILW1336V.KP_CINW] • CHILD_HEALTH_SURVEILLANCE_CHECKS [SAILW1336V.KP_CRCS] • HEALTH_DENTAL_CHECK [SAILW1336V.KP_CINW] • HEALTH_DENTAL_CHECK [SAILW1336V.KP_CRCS] • CATEGORY_OF_NEED_CODE [SAILW1336V.KP_CINW] • CATEGORY_OF_NEED_CODE [SAILW1336V.KP_CRCS] • CATEGORY_OF_NEED_CODE [SAILW1336V.KP_LACW]	
		Child protection record	• CHILD_PROTECTION_REGISTER [SAILW1336V.KP_CINW] • RECENT_REFERRAL_CHILD_PREVIOUSLY_ON_CPR [SAILW1336V.KP_CINW] • CHILD_PROTECTION_REGISTER [SAILW1336V.KP_CRCS] • ON_PROTECTION_REGISTER [SAILW1336V.KP_NCCH_HC]	
	Financial abuse	Experiencing financial abuse	• CPR_FINANCIAL_ABUSE [SAILW1336V.KP_CRCS]	
Household adversity, where a parent or guardian...	Is a victim of intimate partner violence	Domestic violence	• _	Will be measured using child variable so commenting on child's experience of this rather than using parent's linked data.
		Family conflict or discord	• _	
	Is in prison or on probation	Imprisonment of household member	• _	
		Household criminality	• _	
		Household member involvement in criminal justice system	• _	

Has a mental health problem	Household mental illness	• PARENTING_CAPACITY_MENTAL_ILL_HEALTH [SAILW1336V.KP_CINW] • PARENTING_CAPACITY_MENTAL_ILL_HEALTH [SAILW1336V.KP_CRCS] • SERVICE_USER_HAS_MENTAL_HEALTH_CONDITION_CD [SAILW1336V.KP_MIDS_BIRTH_ASSESS] • SERVICE_USER_HAS_MENTAL_HEALTH_CARE_PLAN_CD [SAILW1336V.KP_MIDS_BIRTH_ASSESS]	Could use as proxy because depression is one of most common mental health conditions.
	Primary caregiver(s) mental health problems	• RECENT_REFERRAL_PARENTAL_MENTAL_ILL_HEALTH [SAILW1336V.KP_CINW] • PARENTING_CAPACITY_MENTAL_ILL_HEALTH [SAILW1336V.KP_CRCS] • SERVICE_USER_HAS_MENTAL_HEALTH_CONDITION_CD [SAILW1336V.KP_MIDS_BIRTH_ASSESS]	
	Family history of psychiatric disorders	• SERVICE_USER_HAS_MENTAL_HEALTH_CONDITION_CD [SAILW1336V.KP_MIDS_BIRTH_ASSESS]	
	Family history of severe mental illness (e.g. psychosis)	• SERVICE_USER_HAS_MENTAL_HEALTH_CONDITION_CD [SAILW1336V.KP_MIDS_BIRTH_ASSESS]	
	Maternal psychosis (perinatal or pre-natal)	• _	
	Maternal depression during pregnancy	• SERVICE_USER_HAS_MENTAL_HEALTH_CONDITION_CD [SAILW1336V.KP_MIDS_BIRTH_ASSESS]	
	Maternal use of psychotropics during pregnancy	• _	
Abuses alcohol or drugs	Household alcohol abuse	• PARENTING_CAPACITY_SUBSTANCE_ALCOHOL_MISUSE [SAILW1336V.KP_CINW] • PARENTING_CAPACITY_SUBSTANCE_ALCOHOL_MISUSE [SAILW1336V.KP_CRCS] • RECENT_REFERRAL_PARENTAL_SUBSTANCE_ALCOHOL_MISUSE [SAILW1336V.KP_CINW]	
	Household drug abuse	• PARENTING_CAPACITY_SUBSTANCE_ALCOHOL_MISUSE [SAILW1336V.KP_CINW] • PARENTING_CAPACITY_SUBSTANCE_ALCOHOL_MISUSE [SAILW1336V.KP_CRCS] • RECENT_REFERRAL_PARENTAL_SUBSTANCE_ALCOHOL_MISUSE [SAILW1336V.KP_CINW]	

		Maternal alcohol use during pregnancy	• _	
		Maternal substance abuse during pregnancy	• _	
	Is separated or divorced	Primary caregiver(s) marital status	• _	
		Blended or complex family structure	• _	
		Single parent/caregiver family	• _	
	Has died	Death of primary caregiver(s)	• _	
Involvement with child protective services (CPS) or living in care	_	Separation from family (e.g. out-of-home care)	• Simply being present in LACW database is indicator of Involvement with CPS or living in care • EPISODE_NUMBER [SAILW1336V.KP_LACW] • LEGAL_STATUS_CODE [SAILW1336V.KP_LACW] • LOOKED_AFTER_CHILD [SAILW1336V.KP_CINW] • LOOKED_AFTER_CHILD [SAILW1336V.KP_CRCS] • LOOKED_AFTER [SAILW1336V.KP_NCCH_HC]	
Homelessness	_	Homelessness (young person has left home)	• ACCOMMODATIONNEED [SAIL1336V.SMDS_ASSESSMENTS_20211101] • RISKOFEVICTION_STS [SAIL1336V.SMDS_TOPS_20211101] • URGENTHOUSINGPROBLEM_STS [SAIL1336V.SMDS_TOPS_20211101]	
		Homelessness	• ACCOMMODATIONNEED [SAIL1336V.SMDS_ASSESSMENTS_20211101] • RISKOFEVICTION_STS [SAIL1336V.SMDS_TOPS_20211101] • URGENTHOUSINGPROBLEM_STS [SAIL1336V.SMDS_TOPS_20211101]	

Of note, Delphi risk factor 'Homelessness' refers to family/caregiver level. Alternatively, 'Homelessness (young person has left home)' refers to the individual-

		Being an unaccompanied asylum seeker	• ASYLUM_SEEKER_CODE [SAILW1336V.KP_CRCS] • ASYLUM_SEEKER_CODE [SAILW1336V.KP_CINW] • ASYLUM [SAILW1336V.KP_LACW] • DATE_CEASED_UASC [SAILW1336V.KP_LACW]	level whereby the young person is homeless.
		Being an asylum-seeking family	• _	
Experiencing bullying	_	Victim of bullying	• _	
Experiencing racism	_	Experience of racism and discrimination	• _	
		Family experience of social exclusion, discrimination and harassment associated with ethnicity	• _	
		Victim of structural/systemic racism	• _	
		Cultural racism	• _	
		Racial bias in obstetric care	• _	
Experiencing violence in the community	_	Victim or witness of violent crime	• _	
		Witness of community violence	• _	

Victim of organised crime (e.g. commercial sexual exploitation or via county lines)	• _
War/conflict	• _
Torture	• _
Radicalisation	• _
Living in an area with high crime levels	• _
Gangland crime	• _
Organised crime affiliation	• _

Being a young carer	_	Being a young carer	• _

Of note, these are my proposed ways to measure these ACE concepts within SAIL based on SAIL metadata/variable descriptions. However, when I carry out measurement analysis, I may find that some variables are unusable (e.g. are unused or legacy variables, or contain predominantly null data).

9.2.3 Appendix B.3 – Development of the ADP’s code lists for confirmed and possible maltreatment

9.2.3.1 *Confirmed Childhood Maltreatment code list development*

As per their request, the following paragraphs in this section are taken directly from a methodological description provided by the ADP.

Codes lists were developed by the ADP from existing literature (Joht S Chandan et al., 2019; Joht Singh Chandan, Gokhale, et al., 2020; Joht Singh Chandan, Okoth, et al., 2020; McKenzie & Scott, 2011; McKenzie, Scott, Waller, & Campbell, 2011; Schnitzer, Slusher, Kruse, & Tarleton, 2011; Syed et al., 2022; Woodman et al., 2012), conducting their own searches for codes that may indicate maltreatment, risk, or cause for concern; and also based on clinician judgement.

These lists were externally validated against a clinically-assessed cohort of childhood maltreatment cases from a child protection service secondary care-based setting – the ‘gold standard’ for validation. These lists of ‘Confirmed Childhood Maltreatment’ codes include terms that unequivocally stated the existence of maltreatment. This included maltreatment syndromes, history/victim of abuse, child protection categories, prostitution, genital mutilation, and criminal neglect/abandonment of baby. All these categories were included in the primary care data analysis; however, child protection codes are not available in hospital admissions data.

Of note, childhood maltreatment codes can be further divided into prevalence codes and incidence codes by excluding codes indicating historical maltreatment (e.g. history of child abuse) from the incidence list (Joht Singh Chandan, Gokhale, et al., 2020).

9.2.3.2 *Possible Childhood Maltreatment code list development*

As per their request, the following paragraphs in this section are taken directly from a methodological description provided by the ADP.

Whereas the ‘Confirmed Childhood Maltreatment’ codes include terms that unequivocally state the existence of maltreatment, the ‘Possible Childhood Maltreatment’ lists include codes which may indicate risk and vulnerability of children that may co-occur with maltreatment. However, they are not sufficient in isolation to indicate maltreatment.

‘Possible Childhood Maltreatment’ codes fell into six categories:

- 1) At risk/safeguarding codes: For example, ‘at risk of abuse’ or ‘safeguarding example’. Safeguarding was distinguished from child protection. Child protection is a response to maltreatment or abuse that has already taken place. A child or young person is a safeguarding concern when they are living in circumstances where there is a significant risk of abuse (physical, sexual, emotional or neglect). At-risk codes may not be specific enough to record an event of child maltreatment, however these codes have utility for identifying children at significant risk. This may have implications for long-term outcomes and future research with vulnerable children. There is no equivalent of these codes in hospital admissions data, so these were searched in GP data only.
- 2) Other social care: For example, ‘referred to social worker’ or ‘in foster care.’ Social care codes not specifically related to child protection may also be useful for identifying potentially vulnerable children. However, there are many reasons why a child may have contact with social care that may not be related to maltreatment (e.g. parent or child disability, and mental or physical health problems of either the parent or the child). There is no equivalent of these codes in hospital admissions data, so these were searched in GP data only.
- 3) Family circumstances: This included codes ‘child abuse in family’ or ‘family member on protection register’. These codes are indicative of risk but do not necessarily indicate child maltreatment for the individual in question.
- 4) Alleged/suspected maltreatment: For example, ‘suspected child abuse’, ‘alleged abuse’.
- 5) Rib/limb fractures: For example, ‘multiple rib fractures’.
- 6) Assaults: This included general codes such as ‘assault’ and more specific codes such as ‘physical assault at home’.

9.2.4 Appendix B.4 – Step-by-step methods for measuring ACEs

To measure ACEs within SAIL, I took the lists of codes the ADP and I had developed and operationalised, and wrote SQL code for performing measurement of the ACEs. Below is a step-by-step description of the methods used to measure ACEs, supplemented with code snippets to aid explanation.

Step 1: Using my code lists with operationalised definitions, for each database I measured the number of unique individuals who had experienced any ACEs. I did this by creating views with positive cases only (e.g. in SMDS where ACCOMMODATIONNEED was '01' or '02') and counting the unique ALFs within each database view. This provided a denominator of all the young people per database who had experienced any type of ACE. To get the numerator, I counted how many unique ALFs were present in each database, regardless of ACE exposure.

Step 2: Using the ADP lists, I created the same type of views per database but further divided these into 'confirmed' or 'suspected', in accordance with how their code lists were created, as well as creating a 'combined' view which combined the confirmed and suspected cases to measure any possible ACEs per database. Again, I counted the number of unique ALFs (i.e. young people) per database who had experienced any ACE.

Step 3: Steps 1 and 2 allowed me to measure the prevalence of exposure to any ACE per database, but did not allow me to understand which particular ACEs were experienced by young people, nor which databases picked up certain ACEs over others.

As such, I created a spreadsheet with tabs of specific code lists per ACE and how that ACE could be measured in each of the databases in which it was measurable.

In order to group the ACEs by type, I took the ADP lists and their classifications ('neglect', 'physical', 'psychological', 'sexual', 'other') and then merged their classifications onto an amended version of my own ACE categories ('neglect', 'physical', 'psychological inc. verbal or emotional abuse', 'sexual', 'other maltreatment', 'financial', 'parent/guardian victim of IPV', 'parent/guardian mental health problem', 'parent/guardian substance problem', 'parent/guardian in prison or on probation', 'parent/guardian separated/divorced', 'parent/guardian died', 'involvement with child protective services (CPS) or living in care', 'homelessness', 'bullying', 'racism', 'violence in the community', and 'young carer'). I went through all codes and attached the most appropriate ACE category(/ies), and put this in the

corresponding tab(s) in the spreadsheet. I added more granular classifications to some, for example, 'other' was sometimes recoded as a new more specific classification (e.g. I put nutritional and water shortages as 'neglect' because the child's basic needs were not being met). Unspecified abuses or risks were classed as 'other'.

My classifications generally agreed with the ADP's original classification but occasionally mapped onto a different one from my list. For example, I classified any mention of FGM to 'sexual abuse' based on googling definitions in the Crown Prosecution Service and websites like Centre for Action on Rape and Abuse. In general, codes were classified to one main ACE type, but where appropriate, codes could feature in more than one ACE group (e.g. if they reasonably covered both or were a good proxy for both). This happened infrequently and included codes like 'Z628: Personal history of physical and sexual abuse in childhood' which was classified as both 'physical' and 'sexual', and '13ZZ0: at risk of domestic violence' as both 'physical' and 'parent/guardian victim of IPV' because it seemed like a reasonable proxy that the parent may experience domestic violence if the child is 'at risk' of domestic violence.

After exploration of the codes, I decided not to use the category of 'violence in the community' and instead coded these to other abuses. This decision was taken because, from the coding descriptions, I could not be confident these happened in the community, rather than being linked to the household. In theory, one could attempt to measure 'violence in the community' e.g. codes existed that showed an abuse at a specific location like sports centre, farm, industrial park, thus this could be inferred as 'community violence', but I felt there were too many assumptions being made to justify this, so I opted to classify this as physical abuse, sexual abuse etc. The same applied for 'bullying', and 'racism' e.g. you could include the codes 'Victim of bullying when not in school' and 'at risk of discriminatory abuse' but with these, I would be missing many cases of bullying and racism which were hidden by being coded as physical and psychological abuses etc, so I opted just to count them in broader categories like 'physical' or 'psychological' abuses etc, rather than attempt to measure bullying or racism specifically, and risk significantly under-measuring. I then classified my own codes into the same groupings as the re-classified ADP lists and made sheets that had each ACE separated out. [The spreadsheet with the full code list categorisations can be provided if needed.]

I then turned each list of ACEs (i.e. tab in the spreadsheet) into a text file. For example, for the ACE 'financial abuse', there were few instances of databases in which it was measurable, and few codes relating to it.

```

--Financial abuse

[CRCS:]
[CPR_FINANCIAL_ABUSE] IN ['1']

Variable

WLGP:
READ_CODE IN '14XK.'

WRRS_Results:
READ_CD IN '14XK.'

WRRS_Requests:
READ_CD IN '14XK.'

```

The above means that in the database CRCS, the value indicating financial abuse is '1', and in the databases using Read Codes (i.e. WLGP and WRRS), the value '14XK.' indicates exposure to financial abuse. 'IN' is used to specify in the SQL user environment (known as Eclipse) what value(s) a variable can take. This ACE is an example of a very short code list. In contrast, an ACE like 'physical abuse' had hundreds of codes relating to it, and was measurable in multiple databases (ADDE, CINW, CRCS, EDDS, OPDW, PEDW, WLGP, and WRRS [i.e. WRRS_Results and WRRS_Requests]). Thus, a small snippet relating to a database using ICD-10 codes would read:

```

ICD10 IN ('Z616.', 'X85..', 'X85.', 'X850.', 'X851.', 'X851.', 'X852.', 'X853.',
'X854.', 'X854.', 'X855.', 'X855.', 'X856.', 'X857.', 'X858.', 'X859.', 'X859.',
'X86..', 'X86.', 'X860.', 'X861.', 'X862.', 'X863.', 'X864.', 'X865.', 'X866.',
'X867.', 'X867.', 'X868.', 'X869.', 'X87..', 'X87.', 'X870.', 'X871.', 'X872.',
'X873.', 'X874.', 'X875.', 'X876.', 'X877.', 'X878.', 'X879.', 'X88..', 'X88.',
'X880.', 'X881.', 'X882.', 'X883.', 'X884.', 'X885.', 'X886.', 'X887.', 'X888.',
'X889.', 'X89..',
...)

```

ChatGPT was used to assist with formatting these text files (i.e. transforming the lists of several hundred codes into the correct syntax with apostrophes and commas separating codes); these files were then manually checked line-by-line to avoid any errors. This process resulted in 11 text files of the ACEs I could measure:

- Physical maltreatment
- Psychological maltreatment
- Sexual maltreatment
- Financial maltreatment
- Neglect
- Other maltreatment
- Parent or guardian interpersonal violence (IPV)

- Parent or guardian mental health problems
- Parent or guardian substance misuse problems
- Homelessness or unstable housing
- Involvement with child protective services (CPS) or living in care

Using these text files, I wrote SQL code which made views of only the ALFs where ACEs were positive (i.e. an ACE occurred) by ACE type by database, for example, CINW_NEGLECT. This view contained all instances of a young person with a code from the CINW database indicating they had experienced neglect.

See example section of SQL code below. Lines 12-15 specify which values indicate neglect for each relevant variable; lines 5-10 create a view of this information, with column headings specified; and line 11 provides the original source database. This view would allow duplicate recordings of young people, for instance, if a young person had multiple episodes of recorded neglect. However, this duplication was then addressed at a later stage when I selected counts of unique ALFs only.

```

4  --For each ACE, make a CINW view of positive cases
5  CREATE VIEW SAILW1336V.CINW_NEGLECT_Katherine AS
6  SELECT ALF_PE,
7  HEALTH_IMMUNISATIONS AS NEGLECT_CINW_HEALTH_IMMUNISATIONS,
8  CHILD_HEALTH_SURVEILLANCE_CHECKS AS NEGLECT_CINW_CHILD_HEALTH_SURVEILLANCE_CHECKS,
9  HEALTH_DENTAL_CHECK AS NEGLECT_CINW_HEALTH_DENTAL_CHECK,
10 CATEGORY_OF_NEED_CODE AS NEGLECT_CINW_CATEGORY_OF_NEED_CODE
11 FROM SAILW1336V.KP_CINW
12 WHERE HEALTH_IMMUNISATIONS IN '0'
13 OR CHILD_HEALTH_SURVEILLANCE_CHECKS IN '0'
14 OR HEALTH_DENTAL_CHECK IN '0'
15 OR CATEGORY_OF_NEED_CODE IN 'N8'

```

This process resulted in making 72 views i.e. a view for every database where it was theoretically possible to measure each ACE, with a view per ACE type. Of note, I say ‘theoretically possible’ because there may have been 0 cases of an ACE of a specific type appearing in the database, but there was a variable (e.g. ICD-10 or Read Code) which made it possible to measure if any positive cases existed. Following this, I had views which only had the ALFs of young people who experienced a particular ACE within that database. For example, for the CINW database, there were eight views, namely: CINW_NEGLECT; CINW_PARENT_GUARDIAN_SUBSTANCE_PROBLEM; CINW_HOMELESSNESS; CINW_PARENT_GUARDIAN_MH_PROBLEM; CINW_IPV_VICTIM; CINW_LIVING_IN_CARE; CINW_PHYSICAL; and CINW_OTHER_MALTREATMENT. Each view was succeeded by my name in order to make it easily searchable and identifiable within SQL Eclipse (which was a shared work environment

with the rest of the Timely team) and to make it discernible from the original views created by Dr Friedmann when she linked our data.

Step 4: Using the 72 views created in step 3, I counted unique ALFs (i.e. unique individuals) who had experienced each ACE per database. This provided a portion of my results i.e. ACEs by type by database.

See example section of SQL code below. Line 78 counts the unique/distinct cases; this operation is carried out on the view CINW_NEGLECT (line 79), so the resulting number will be the cases of neglect detected in the CINW database. This was repeated for cases of physical maltreatment (lines 81-82) and other maltreatment (lines 84-85) in the CINW database. I repeated this process for all 72 views (i.e. each ACE measurable in each database).

```
77  ----Counts of each ACE in each view
78  SELECT COUNT (DISTINCT ALF_PE) -- Answer is 17,547
79  FROM SAILW1336V.CINW_NEGLECT_Katherine
80
81  SELECT COUNT (DISTINCT ALF_PE) -- Answer is 13,362
82  FROM SAILW1336V.CINW_PHYSICAL_Katherine
83
84  SELECT COUNT (DISTINCT ALF_PE) -- Answer is 26,599
85  FROM SAILW1336V.CINW_OTHER_MALTREATMENT_Katherine
```

Step 5: In order to calculate the total prevalence of each ACE regardless of the database the information was recorded in, I had to turn the views into tables in SQL so that they could be altered, then add an event flag.

See example section of SQL code. First, I created a table from each view from step 3 (lines 12-13), and specified that this table should be populated with data (line 13). I then altered the table by adding an event flag column which specified in which database the ACE positive case was measured (line 14). In a line which was later commented out, I visualised the first 50 rows to check they looked how I would expect (line 16). For each view relating to this ACE, I repeated the above steps, making a table for each and adding event flags (lines 12-25). Next, I checked that the counts per ACE per database matched with my results from step 4 (lines 29-31). Using a union function, I combined the tables for each ACE and counted the unique ALFs to get the result for how many young people had experienced that ACE regardless of database; initially I did this as a query (lines 34-37) and then once happy, created a table from this union query (lines 40-43). Again, I counted the unique ALFs for this table (line 47), checking

it matched with the previous query (lines 34-37). I did this per ACE type (lines 12-758; partially shown below), meaning that I had one table for each ACE type, allowing me to calculate the total number of young people to have experienced each ACE.

```

6  -----Creating event flags for ACEs/database
7
8  ----- 1) PARENTAL MENTAL HEALTH PROBLEM TABLE
9
10 -- 1a) For each view that measures the ACE, turn the view into a table and add an event flag specifying the dataset.
11 --Find all the views from my excel file 'Metadata for my SQL scripts'
12 CREATE TABLE SAILW1336V.CINW_PMH_KATHERINE AS (SELECT * FROM -- Turn view into table
13 SAILW1336V.CINW_PARENT_GUARDIAN_MH_PROBLEM_KATHERINE) WITH DATA;
14 ALTER TABLE SAILW1336V.CINW_PMH_KATHERINE ADD Parent_MH CHAR(10) DEFAULT 'CINW'; --Add a column with the ACE, and default the result to the dataset,
15 --thereby making an ACE flag
16 --SELECT * FROM SAILW1336V.CINW_PMH_KATHERINE LIMIT 50; --Visualise first 50 rows to check it looks how I expect
17
18 CREATE TABLE SAILW1336V.CRCS_PMH_KATHERINE AS (SELECT * FROM
19 SAILW1336V.CRCS_PARENT_GUARDIAN_MH_PROBLEM_KATHERINE) WITH DATA;
20 ALTER TABLE SAILW1336V.CRCS_PMH_KATHERINE ADD Parent_MH CHAR(10) DEFAULT 'CRCS';
21 --SELECT * FROM SAILW1336V.CRCS_PMH_KATHERINE LIMIT 50;
22
23 CREATE TABLE SAILW1336V.MIDS_PMH_KATHERINE AS (SELECT * FROM
24 SAILW1336V.MIDS_PARENT_GUARDIAN_MH_PROBLEM_KATHERINE) WITH DATA;
25 ALTER TABLE SAILW1336V.MIDS_PMH_KATHERINE ADD Parent_MH CHAR(10) DEFAULT 'MIDS';
26 --SELECT * FROM SAILW1336V.MIDS_PMH_KATHERINE LIMIT 50;
27
28 -- 1b) Check the counts match with my counts from middle of table
29 SELECT COUNT(UNIQUE c.ALF_PE) FROM SAILW1336V.CINW_PMH_KATHERINE c; --11,793 (match)
30 SELECT COUNT(UNIQUE c.ALF_PE) FROM SAILW1336V.CRCS_PMH_KATHERINE c; --11,384 (match)
31 SELECT COUNT(UNIQUE c.ALF_PE) FROM SAILW1336V.MIDS_PMH_KATHERINE c; --32,484 (match)
32
33 -- 1c) Check counts in combined tables
34 SELECT COUNT(UNIQUE ALF_PE) FROM
35 (SELECT ALF_PE, Parent_MH FROM SAILW1336V.CINW_PMH_KATHERINE
36 UNION SELECT ALF_PE, Parent_MH FROM SAILW1336V.CRCS_PMH_KATHERINE
37 UNION SELECT ALF_PE, Parent_MH FROM SAILW1336V.MIDS_PMH_KATHERINE); --unique 52,385 (total i.e. allowing duplication: 55,661)
38
39 -- 1d) Once happy with above step, create a combined table
40 CREATE TABLE SAILW1336V.PARENTAL_MH_COMBINED_KATHERINE AS
41 (SELECT ALF_PE, Parent_MH FROM SAILW1336V.CINW_PMH_KATHERINE
42 UNION SELECT ALF_PE, Parent_MH FROM SAILW1336V.CRCS_PMH_KATHERINE
43 UNION SELECT ALF_PE, Parent_MH FROM SAILW1336V.MIDS_PMH_KATHERINE) WITH DATA;
44 --SELECT * FROM SAILW1336V.PARENTAL_MH_COMBINED_KATHERINE LIMIT 50;
45
46 -- 1e) Double-check total count
47 SELECT COUNT(UNIQUE ALF_PE) FROM SAILW1336V.PARENTAL_MH_COMBINED_KATHERINE --unique 52,385

```

Step 6: In order to measure the total number of young people who had experienced any ACEs (regardless of ACE type or database), I created a linked database of the tables I had made per ACE in step 5. In a later step (step 8), I counted the total.

See example section of SQL code. I created a table by left joining each of the tables from step 5 onto the WDSO, i.e. the baseline cohort database which contained all ALFs (lines 765-790), and again populated this with data from the tables (line 790). If I had not specified 'with data', the table columns would be created, but the table would be empty. Using a left join meant that every ALF from the baseline cohort was retained and the tables from step 5 were matched to the corresponding ALF from the baseline cohort, allowing me to view some basic demographic information for each young person. Finally, I checked the counts for each ACE to see that they matched with the results from step 5 to ensure nothing had gone awry in the linkage process (lines 793-824; not shown here).

```

761 -----
762 -----JOIN ALL tables together WITH WDSO. Keep demographic info AND mental health events (flagged by Yasmin, using
763 --ADP's algorithm)
764
765
766 CREATE TABLE SAILW1336V.LINKED_DATABASE_ACES_KATHERINE AS
767 (SELECT kde.ALF_PE, GNDR_CD, SEX_CD, WOB, EVENT, FINANCIAL_ABUSE, PARENT_MH, LIVING_IN_CARE, NEGLECT, OTHER_MALTREATMENT,
768 PARENT_OR_GUARDIAN_SUBSTANCE_MISUSE, PHYSICAL, PSYCHOLOGICAL, SEXUAL_ABUSE, HOMELESSNESS, IPV
769 FROM SAILW1336V.KP_DEMOG_EVENTS kde
770 LEFT JOIN SAILW1336V.FINANCIAL_COMBINED_KATHERINE
771 ON kde.ALF_PE = SAILW1336V.FINANCIAL_COMBINED_KATHERINE.ALF_PE
772 LEFT JOIN SAILW1336V.PARENTAL_MH_COMBINED_KATHERINE
773 ON kde.ALF_PE = SAILW1336V.PARENTAL_MH_COMBINED_KATHERINE.ALF_PE
774 LEFT JOIN SAILW1336V.LIVING_IN_CARE_COMBINED_KATHERINE
775 ON kde.ALF_PE = SAILW1336V.LIVING_IN_CARE_COMBINED_KATHERINE.ALF_PE
776 LEFT JOIN SAILW1336V.NEGLECT_COMBINED_KATHERINE
777 ON kde.ALF_PE = SAILW1336V.NEGLECT_COMBINED_KATHERINE.ALF_PE
778 LEFT JOIN SAILW1336V.OTHER_MALTREATMENT_COMBINED_KATHERINE
779 ON kde.ALF_PE = SAILW1336V.OTHER_MALTREATMENT_COMBINED_KATHERINE.ALF_PE
780 LEFT JOIN SAILW1336V.PG_SUBSTANCE_MISUSE_COMBINED_KATHERINE
781 ON kde.ALF_PE = SAILW1336V.PG_SUBSTANCE_MISUSE_COMBINED_KATHERINE.ALF_PE
782 LEFT JOIN SAILW1336V.PHYSICAL_COMBINED_KATHERINE
783 ON kde.ALF_PE = SAILW1336V.PHYSICAL_COMBINED_KATHERINE.ALF_PE
784 LEFT JOIN SAILW1336V.PSYCHOLOGICAL_COMBINED_KATHERINE
785 ON kde.ALF_PE = SAILW1336V.PSYCHOLOGICAL_COMBINED_KATHERINE.ALF_PE
786 LEFT JOIN SAILW1336V.SEXUAL_COMBINED_KATHERINE
787 ON kde.ALF_PE = SAILW1336V.SEXUAL_COMBINED_KATHERINE.ALF_PE
788 LEFT JOIN SAILW1336V.HOMELESSNESS_COMBINED_KATHERINE
789 ON kde.ALF_PE = SAILW1336V.HOMELESSNESS_COMBINED_KATHERINE.ALF_PE
790 LEFT JOIN SAILW1336V.IPV_COMBINED_KATHERINE
791 ON kde.ALF_PE = SAILW1336V.IPV_COMBINED_KATHERINE.ALF_PE)
792 WITH DATA;

```

Step 7: Next, to understand how many cases of ACE exposure were measured in each database, I used the linked database and counted the unique ALFs where each given database was the source of that ACE being measured. For example, in the section of code, lines 829-840 count the unique young people who had any of the ACEs recorded in the PEDW database. A total of 14,617 young people (line 840) had experienced an ACE which was detected in the PEDW database. I repeated this for each database (lines 829-983; partially shown below), providing totals per database.

```

826 -----
827 -----Check how many ACEs are picked up in the linked database in each database (i.e. total number of young people who experienced at least 1 ACE per dataset)
828
829 SELECT COUNT(UNIQUE ALF_PE) FROM SAILW1336V.LINKED_DATABASE_ACES_KATHERINE
830 WHERE FINANCIAL_ABUSE IN 'PEDW'
831 OR PARENT_MH IN 'PEDW'
832 OR LIVING_IN_CARE IN 'PEDW'
833 OR NEGLECT IN 'PEDW'
834 OR OTHER_MALTREATMENT IN 'PEDW'
835 OR PARENT_OR_GUARDIAN_SUBSTANCE_MISUSE IN 'PEDW'
836 OR PHYSICAL IN 'PEDW'
837 OR PSYCHOLOGICAL IN 'PEDW'
838 OR SEXUAL_ABUSE IN 'PEDW'
839 OR HOMELESSNESS IN 'PEDW'
840 OR IPV IN 'PEDW';--Answer is 14,617
841
842 SELECT COUNT(UNIQUE ALF_PE) FROM SAILW1336V.LINKED_DATABASE_ACES_KATHERINE
843 WHERE FINANCIAL_ABUSE IN 'OPDW'
844 OR PARENT_MH IN 'OPDW'
845 OR LIVING_IN_CARE IN 'OPDW'
846 OR NEGLECT IN 'OPDW'
847 OR OTHER_MALTREATMENT IN 'OPDW'
848 OR PARENT_OR_GUARDIAN_SUBSTANCE_MISUSE IN 'OPDW'
849 OR PHYSICAL IN 'OPDW'
850 OR PSYCHOLOGICAL IN 'OPDW'
851 OR SEXUAL_ABUSE IN 'OPDW'
852 OR HOMELESSNESS IN 'OPDW'
853 OR IPV IN 'OPDW';--Answer is 34
854
855 SELECT COUNT(UNIQUE ALF_PE) FROM SAILW1336V.LINKED_DATABASE_ACES_KATHERINE
856 WHERE FINANCIAL_ABUSE IN 'WRRS'
857 OR PARENT_MH IN 'WRRS'
858 OR LIVING_IN_CARE IN 'WRRS'
859 OR NEGLECT IN 'WRRS'
860 OR OTHER_MALTREATMENT IN 'WRRS'
861 OR PARENT_OR_GUARDIAN_SUBSTANCE_MISUSE IN 'WRRS'
862 OR PHYSICAL IN 'WRRS'
863 OR PSYCHOLOGICAL IN 'WRRS'
864 OR SEXUAL_ABUSE IN 'WRRS'
865 OR HOMELESSNESS IN 'WRRS'
866 OR IPV IN 'WRRS';--Answer is 0

```

Step 8: Using the linked database created in step 6, I counted the total number of young people exposed to any ACE. I did this by counting unique cases where any of the ACE types was 'NOT NULL'. See section of SQL code below.

```

985 -----
986 -----Check how many ACEs are picked up in the linked database (i.e. total number of young people who experienced at least 1 ACE)
987
988 SELECT COUNT(UNIQUE ALF_PE) FROM SAILW1336V.LINKED_DATABASE_ACES_KATHERINE
989 WHERE FINANCIAL_ABUSE IS NOT NULL
990 OR PARENT_MH IS NOT NULL
991 OR LIVING_IN_CARE IS NOT NULL
992 OR NEGLECT IS NOT NULL
993 OR OTHER_MALTREATMENT IS NOT NULL
994 OR PARENT_OR_GUARDIAN_SUBSTANCE_MISUSE IS NOT NULL
995 OR PHYSICAL IS NOT NULL
996 OR PSYCHOLOGICAL IS NOT NULL
997 OR SEXUAL_ABUSE IS NOT NULL
998 OR HOMELESSNESS IS NOT NULL
999 OR IPV IS NOT NULL; --Answer is 168,660 (or 7,026,182 allowing duplicates)

```

Step 9: Finally, I re-ran the script above, grouping it by sex to get counts broken down by girls, boys and people of unknown sex. See section of SQL code.

I did this per ACE regardless of database and per ACE by database. In addition, I repeated this per database regardless of ACE exposure, in order to understand what the sex composition was of each database (i.e. to characterise the database). Of note, if disaggregating by sex would reveal numbers below 5, I had to mask these numbers to avoid risking reidentification. I flagged where this was the case in the Results section.

```

201 --WLGP
202 SELECT COUNT(UNIQUE ALF_PE), GNDR_CD FROM SAILW1336V.LINKED_DATABASE_ACES_KATHERINE
203 WHERE NEGLECT IN 'WLGP'
204 GROUP BY GNDR_CD; --Answer is FEMALE = 686; MALE = 787; MISSING = 0
205
206 SELECT COUNT(UNIQUE ALF_PE), GNDR_CD FROM SAILW1336V.LINKED_DATABASE_ACES_KATHERINE
207 WHERE PHYSICAL IN 'WLGP'
208 GROUP BY GNDR_CD; --Answer is FEMALE = 4,863; MALE = 5,759; MISSING = 1
209
210 SELECT COUNT(UNIQUE ALF_PE), GNDR_CD FROM SAILW1336V.LINKED_DATABASE_ACES_KATHERINE
211 WHERE PSYCHOLOGICAL IN 'WLGP'
212 GROUP BY GNDR_CD; --Answer is FEMALE = 1,967; MALE = 543; MISSING = 0
213
214 SELECT COUNT(UNIQUE ALF_PE), GNDR_CD FROM SAILW1336V.LINKED_DATABASE_ACES_KATHERINE
215 WHERE SEXUAL_ABUSE IN 'WLGP'
216 GROUP BY GNDR_CD; --Answer is FEMALE = 2,636; MALE = 2,917; MISSING = 0
217
218 SELECT COUNT(UNIQUE ALF_PE), GNDR_CD FROM SAILW1336V.LINKED_DATABASE_ACES_KATHERINE
219 WHERE FINANCIAL_ABUSE IN 'WLGP'
220 GROUP BY GNDR_CD; --Answer is FEMALE = 0; MALE = 0; MISSING = 0
221
222 SELECT COUNT(UNIQUE ALF_PE), GNDR_CD FROM SAILW1336V.LINKED_DATABASE_ACES_KATHERINE
223 WHERE OTHER_MALTREATMENT IN 'WLGP'
224 GROUP BY GNDR_CD; --Answer is FEMALE = 41,941; MALE = 44,235; MISSING = 1
225
226 SELECT COUNT(UNIQUE ALF_PE), GNDR_CD FROM SAILW1336V.LINKED_DATABASE_ACES_KATHERINE
227 WHERE IPV IN 'WLGP'
228 GROUP BY GNDR_CD; --Answer is FEMALE = 2,133; MALE = 1,482; MISSING = 0
229
230 SELECT COUNT(UNIQUE ALF_PE), GNDR_CD FROM SAILW1336V.LINKED_DATABASE_ACES_KATHERINE
231 WHERE LIVING_IN_CARE IN 'WLGP'
232 GROUP BY GNDR_CD; --Answer is FEMALE = 7,791; MALE = 8,765; MISSING = 1

```

9.2.5 Appendix B.5 – Additional technical detail about ALF assignment and data linkage in the SAIL Databank

The full process of ALF assignment and data linkage is detailed by Lyons and colleagues (2009) (see in particular Figure 1, pg. 7). In summary, the Welsh Demographic Service (WDS) assigns unique NHS numbers to each person; thus, the associated database (WDSD) contains anyone who is registered with a Welsh GP, including people who currently live in Wales, but it also may include those who live in close proximity to Wales. SAIL uses the WDSD as a proxy for the Welsh population. Record linkage between databases within the SAIL is completed by deterministic record linkage if NHS numbers are available and then probabilistic record linkage if deterministic record linkage is not possible. Each individual in the WDSD is assigned a unique identifier (aka an Anonymised Linking Field, or ALF) and matched to other databases through a matching algorithm, the MACRAL (Matching Algorithm for Consistent Results in Anonymised Linkage). NWIS, a trusted third party, carry out all person-identifiable matching (Evans, 2022).

According to Ford, Lyons and colleagues, the optimum matching technique was found to yield specificity values >99.8% and sensitivity values >94.6% with probabilistic record linkage at the 50% threshold, with error rates of <0.2% (D. V. Ford et al., 2009; Lyons et al., 2009). To comply with GDPR, SAIL shares privacy notices on behalf of data providers, for example in GP surgeries, to inform the public about its practices and allow them to opt-out of the databank should they wish (K. H. Jones et al., 2019). In reality, as of 2019, SAIL had had less than 0.025% of the population make this request, implying high representativeness in the data.

9.3 Appendix C – Chapter 6: Umbrella Review Update of Prevention and Early Interventions for Mental Health Problems following ACEs

9.3.1 Appendix C.1 – Additional methodological details

9.3.1.1 Eligibility criteria

Table 59: Study inclusion and exclusion criteria

Item of PICOS	Inclusion criteria	Exclusion criteria
Participant (P)	- Children and young people (aged 0-25 years at the time of intervention; although may be older when study follow-up occurs) - At least 70% of the participants experienced ≥ 1 adverse childhood experience (ACE) or trauma. We defined ACEs as negative or potentially traumatic events occurring in the first 18 years of life; they involved six traditional categories of child maltreatment and six adverse family circumstances (based on definitions by Asmussen, McBride, & Waddell, 2019; Center for Disease Control and Prevention, 2019; Felitti et al., 1998; Finkelhor, Shattuck, Turner, & Hamby, 2013; Nickerson, Bryant, Aderka, Hinton, & Hofmann, 2013), as well as those adapted from Lester and colleagues (2019), whose review we were updating. These comprised: Physical abuse; Sexual abuse; Emotional abuse; Physical neglect; Emotional neglect; Domestic violence (either experiencing or witnessing); Parental or caregiver/guardian substance misuse (i.e. alcohol or drugs, including medication abuse); Parental or caregiver/guardian mental illness; Parental separation or divorce; Parental or caregiver/guardian death; Household member incarcerated or on probation; Unstable housing (i.e. homelessness, involvement with child protective services (CPS) or living in care, conflict-related displacement).	<0 years (i.e. from conception to birth) or >25 years old - Experienced 0 adverse childhood experiences or not specified as experiencing any ACEs

	Identified as at risk for or is experiencing poor outcomes, including possibly having formal mental health diagnoses	
Study (S) and intervention (I)	- Systematic reviews or meta-analyses of interventions (made up of primary studies of any study design i.e. not limited to RCTs) - Published and unpublished studies (e.g. systematic reviews within unpublished PhD theses) - Articles published between March 2018 to present (i.e. since search was run by Lester and colleagues (2019); some of the articles from 2007-2018 screened by Lester and colleagues (2019) were re-screened by our team too as our definitions and inclusion criteria differed somewhat (e.g. definition of young people, non-English language papers etc) - Articles from any country - Articles published in any language (so long as there was an English-abstract) - Studies of interventions for the benefit of those who have experienced adverse childhood experiences (ACEs) - Studies of interventions identified as ‘prevention’ or ‘early intervention’ - Studies of ‘targeted/selective’ or ‘indicated’ interventions (i.e. studies aimed at preventing or reducing illness, rather than universal interventions aimed at increasing ‘wellness’). (NB: the child or young person did not need to be the direct recipient of the intervention, but their outcomes needed to be reported). - Studies that reported effectiveness for young people’s mental health outcomes	- Articles other than systematic reviews or meta-analyses - Other umbrella reviews, because evidence is not at correct level for synthesis (though the systematic reviews from an umbrella review could be included if relevant) - Protocol studies; feasibility studies - Critical or literature reviews (i.e. reviews without analysis of an intervention) - Opinion pieces/articles/letters/commentaries/editorials (i.e. without analysis of an intervention) - Articles published before 2007 ‘Universal’ interventions or interventions aimed at increasing ‘wellness’. (NB: this criteria was applied in the screening stage, not in the search strategy, as we did not wish to exclude systematic reviews which explored a mix of universal, targeted and indicated interventions). - Studies of generic health messaging (e.g. advice aimed at everyone, such as to eat 5 fruits and vegetables per day or to exercise) - Interventions targeted at neurological conditions such as dementias - Interventions targeted at prenatal risk factors (e.g. prenatal alcohol reduction campaigns or interventions)

9.3.1.2 Study selection and data management

At the title/abstract screening stage, EPPI-reviewer web (Beta) (Thomas et al., 2023) was used to identify and remove duplicated files (n=2,498), obtain abstracts of articles, and to screen articles according to inclusion or exclusion. A team of research assistants (JX, YZ, TRP & EB) and I carried out title/abstract screening, starting with double-coding then moving to single-coding when appropriate. Inter-rater reliability was calculated using an online kappa score calculator (Scarpellini, 2020). Specifically, for the papers from 2018 onwards, JX, YZ, TRP and I carried out an inter-rater reliability batch of 10% of the titles/abstracts (in different pairings, working independently, with each individual taking 5% of the papers, such that 10% of the papers were double-screened). At this stage, the team varied from 'slight agreement' to '(almost) perfect agreement' (using Cohen's kappa¹¹) so we discussed variation, and then carried out a second reliability batch of ~10% ($\leq 5\%$ per person), after which we reached 'moderate agreement'¹² to '(almost) perfect agreement' and switched to single-coding papers. For the 2007-2018 re-screening batch of papers, EB (who joined the team at a later date) and I carried out a 10% inter-rater reliability batch of titles/abstracts, after which we had 'substantial agreement' and moved to single-coding¹³. Once we were reliable between raters, all remaining titles/abstracts were independently screened.

Titles/abstracts were screened in a hierarchical manner, with the earliest point of exclusion where we could be confident being used as the exclusion reason. After each possible exclusion point, if it was still unclear from the title and abstract whether an article should be included in the data extraction stage, the full text was sought for screening. In the case of disagreements, me (as lead researcher) and the other rater would discuss the article and agree on how to resolve discrepancies. Exclusion points in order were: Publication Date (because of re-screening process; to avoid duplicating/screening papers which were already captured in our search); Study Type; Population Type; Intervention Type; Evidence Type. The details of these exclusion/inclusion points are illustrated in the decision flowchart in Figure 22.

¹¹ Thresholds for Cohen's kappa are: 0.01 – 0.20 slight agreement; 0.21 – 0.40 fair agreement; 0.41 – 0.60 moderate agreement; 0.61 – 0.80 substantial agreement; 0.81 – 1.00 almost perfect or perfect agreement.

¹² Only one pairing had 'moderate agreement' and the other pairings had 'substantial agreement' or '(almost) perfect agreement'. It seemed like the reason for only achieving 'moderate agreement' was the fact the batch of papers had a low inclusion rate, with only 1 paper for inclusion, limiting the overall Cohen's kappa score. As such, we agreed to progress to single-coding rather than doing another batch of double-screened titles/abstracts.

¹³ We may have reached agreement quicker in this pairing because EB and I carried out screening at a later time, when I had refined the inclusion/exclusion criteria with the first group of research assistants.

After completion of the title/abstract screening, I downloaded the included texts as RIS files and imported the full texts into the reference manager Zotero v6.0.23 (Digital Scholar, 2023) in order to complete full-text screening. (Of note, there is functionality to complete full-text screening within EPPI-reviewer web (Beta); however, we used Zotero because our free access to the platform had expired.) Regular back-ups of the Zotero library were carried out. EB, CB, YZ and I completed full-text screening, with most being completed by EB and CB. However, I initially completed a reliability batch of papers with each other rater, until sufficiently consistent. Inter-rater reliability was again calculated using an online kappa score calculator (Scarpellini, 2020) and if Cohen's kappa was between 0.61 and 1 (i.e. 'substantial agreement' to '(almost) perfect agreement'), the remaining full texts were screened by only one researcher, with any uncertainties decided through discussion with myself (or with EB, CB or YZ in the case of me being the primary rater). In instances where Cohen's kappa was below 0.61, the other rater and I discussed disagreements and clarified criteria, then an additional 10% of full texts were double-screened and the Cohen's kappa score re-calculated. This process was repeated until sufficient inter-rater reliability was achieved (with batches starting at 10% and then reducing to smaller batches as the number of iterations increased). Once inter-rater reliability was achieved, papers were screened by one rater alone. After reading the full text, if the article was relevant it was included for data extraction. If a rater was unclear from full-text screening, the article was discussed with me and/or included for data extraction in order to aid the decision-making.

9.3.1.3 Data collection/extraction process

Data extraction was carried out by a team of researchers (DP, CB, YZ, EB, PU, AB, ED, SP, CT, ER, KE, TRP and I). We developed a data extraction table in Google Sheets (Google, 2023) for basic study characteristics, and NVivo 12 (QSR International Pty Ltd, 2018) was used for all other study details, with data extracted into 'nodes' and 'child-nodes' relating to each element of the above research questions. We piloted the extraction sheet and NVivo nodes, and discussed and amended as needed, based on a better understanding of the information in the included articles (e.g. 'Pooled Sample Size' was amended to 'Sample Range' when it became clear papers did not have sufficient granularity to extract the former). All members of the team extracted a training batch of papers ($n \sim 7$), which we collectively discussed, compared results and clarified any uncertainties. After this initial training batch, papers were extracted independently by two researchers. After a number of rounds of this double-extraction, and once each individual felt confident and competent to move to single-extraction, the remaining papers were allocated to one researcher alone. Once it was clear we were all extracting similar information, the rate at which individuals moved to single-extraction was self-directed by each researcher judging their own confidence at extraction.

Every extracted paper was briefly presented and discussed in a weekly one-hour team meeting. I was present for all meetings; this meant that: 1) the data extractor could discuss uncertainties; 2) all members of the extraction team could maintain inter-extractor consistency and fidelity in extraction, especially at the early stages when things were less clear and evolving; and 3) guided by the data extractor, I had oversight of the final decision of inclusion or exclusion for every paper. Though the vast majority of papers were extracted by one researcher alone, during the analysis stage, TRP and I checked any final information which was unclear or inconsistent.

9.3.1.4 Quality appraisal of individual studies

Systematic reviews and meta-analyses which were deemed relevant for inclusion in the review were critically assessed using a modified version of the AMSTAR 2 tool (Shea et al., 2017a) in order to rate their methodological quality. Critical appraisal was carried out by CB, TRP, EC and I. Where a review's quality was unclear, we discussed the review and reached a consensus. During an initial pilot phase, CB, EC and I coded one paper together and decided how to interpret the AMSTAR 2 tool, based on the tool's questions, the associated guidance documents (Shea et al., 2017b, 2017a) and how we believed these questions should be interpreted for our purposes. We agreed how strict or lenient to be on each question's appraisal and added these as notes to the tool which we used going forward; this constituted the modified version of the AMSTAR 2 tool and is in Appendix C.3. Using this modified tool, we independently critically appraised two papers, discussed them together, agreed on scoring and refined the tool again. We then independently double-coded another two papers (i.e. one paper to CB and I, one paper to EC and CB) and met to discuss. After we were confident in our quality assessments, we single-rated the remaining papers. TRP, who joined later, completed a training batch of quality assessments (n=3) with the modified tool and then also moved to single-rating papers as she was getting very similar ratings to CB, EC and I. Many papers were rated alone. However, when possible, we met in person to independently rate our papers, meaning we could discuss uncertainties, especially around the more complicated meta-analysis questions. We also quality assessed the vast majority of papers within a short window of time in order to maintain rating fidelity and avoid drift.

We critically appraised all included papers from 2018-2021, as well as any from the pre-2018 re-screened papers. For the papers which were included by the Lester team and also by our team, we did not re-appraise these but instead used the scores allocated by Lester and colleagues. To determine that using the Lester team's scores was a legitimate approach, CB and I re-assessed a batch of five papers to determine that we were sufficiently consistent in our ratings. Our pre-defined threshold for sufficient consistency was ± 2 points on the AMSTAR 2 tool. This threshold was chosen because it

seemed strict enough to be rigorous, but lenient enough in recognition of the inherent subjectivity of quality appraisal. Given we were consistent with Lester's team's ratings, we concluded it was legitimate to use their ratings for these papers. Papers rated by Lester and colleagues are indicated with an 'L' in the Quality Appraisal section; those rated by our team are indicated with a 'P' (for 'Parkin's team').

9.3.1.5 Ethical considerations

The review did not have ethical considerations as a major focus as the data collected was the result of engaging with literature. However, some attention was given to the possible impact on the researchers of engaging with this literature. This was important as the field of ACEs often exposes researchers to the full range of violence perpetrated against young people, which can be overwhelming to read. As such, I checked in with members of the research team in team meetings about how they were finding reading the literature, and encouraged them to reach out to me if needed. I also shared my experiences of the process, and prompted others to do the same if desired. We discussed different approaches for managing any impact. These mainly centred around creating literal or psychological boundaries around the work; for example, whilst working from home, reading review material in a room other than one's bedroom, or having work/home separation, or a designated space to read these papers to create boundaries; avoiding reading at the end of the day or on a Friday; sharing experiences in supervision or team meetings; and breaking up data extraction with other lighter tasks. I also normalised different responses to engaging with this material (e.g. anger, upset, and shock, sometimes jarringly coupled with desensitisation, boredom at the task monotony, apathy, or emotional distance).

9.3.1.6 Notes on methods and points of clarification

Table 60 details points of clarification on areas of the methodology which can be misunderstood or are important for reproducibility.

Table 60: Points of clarification regarding methodology

Item	Clarification
Participants	- If a paper's population was young people who were incarcerated or in residential care equivalent to prison (i.e. due to perpetration of something), we excluded it unless the population met other ACE criteria. Though many young people will have experienced ACEs leading up to incarceration, for our purpose they needed to be seen as the 'victim' not the 'perpetrator' of being in care. We would include papers if a parent or guardian was in prison or if the young person was in residential care for their protection or welfare, not as a punishment or protection of others. This was consistent with Lester and colleagues' approach. - The presence of a mental health diagnosis was still acceptable for prevention or early intervention, as we reasoned that a young person may have a mental health problem but a study could aim to prevent or intervene early against other potential disorders developing. However, if they had a PTSD diagnosis and the intervention was a trauma-focused one, we excluded the papers as we reasoned that this was offering treatment i.e. a trauma intervention for a trauma-related disorder.
Interventions	- Taking a systems view, the young person did not have to be the intervention target, so long as the young person's outcomes were reported. For example, papers could include substance use treatment for parents if the young person's outcomes were reported. - Papers which solely focused on ACE prevention were excluded. This was consistent with Lester and colleagues' approach. However, if interventions were trying to prevent subsequent ACEs after young people had already been exposed to one or more, these papers could be included. For example, an intervention may try to prevent mental health problems occurring by preventing subsequent ACEs e.g. bullying or dating violence prevention interventions for already exposed groups. - Interventions did not explicitly need to claim to be aiming to prevent or intervene early for mental health problems. We looked for evidence for and against the idea of early intervention, especially for unclear papers and compared and contrasted them to decide a point at which a paper could be classed as early intervention versus treatment. This had a level of subjectivity but we aimed to be consistent in approach. In addition, as it was difficult to clearly define prevention or early intervention, we used a sort of 'anti-definition' i.e. looked for what defined (late) treatment and included unclear papers if they did not appear to be treatment (e.g. problems were generally not chronic; interventions were typically not in clinical settings; intervention deliverers were not typically clinicians).
Outcomes	- Substance use problems were accepted as mental health outcomes, as per the DSM-5 classification. - Attachment was not classed as a mental health outcome in and of itself (though we acknowledge problems in attachment could be along the mechanistic pathway towards mental health problems in some cases). This was consistent with Lester and colleagues' approach. However, we would have accepted attachment issues or disorders as a mental health outcome i.e. if an intervention sought to prevent or intervene early with attachment disorders. - Intellectual difficulties or neurodevelopmental conditions, such as autism and ADHD, were not classed as mental health outcomes for our purposes, so alone, these papers would be excluded unless there was also the presence of an acceptable mental health outcome.
Data extraction	For the Spanish and German full texts which passed the screening process, we translated them for extraction (through our existing language knowledge and with the aid of Google Translate).

9.3.2 Appendix C.2 – Search strategy

Search strategies were developed by Dr Sarah Lester's team (Lester et al., 2019) and kindly shared with me. I made minimal edits to these, correcting minor typos, adding a few words and removing limits. Table 61 below shows the edited version of the Embase search strategy, included with permission from Dr Lester's team. The edited versions of all search strategies are not included here for brevity, but can be provided upon request.

Table 61: Amended search strategy for Embase

Line	Search	Changes to original line
1	((divorce* and (parent* or child* or family or families)) or (parent* adj2 separat*) or (marital adj2 separation*) or (family adj2 breakdown) or (family adj2 breakup) or (family adj2 separation) or (marital adj2 break*) or (marriage adj2 break*)).ti,ab.	—
2	Divorce/ or divorced parent/	—
3	1 or 2	—
4	("parentally bereaved" or "parental bereavement" or "Parental death" or "bereaved children" or "parental loss" or "loss of a parent" or "childhood bereavement" or (children* adj grief) or (grieving adj child*) or ((parent* or mother* or father* or carer* or caregiver*) adj3 death)).ti,ab.	—
5	(parental death/ or maternal death/) not (infant death/ or pregnancy/ or "cause of death"/)	—
6	4 or 5	—
7	exp mental disease/ and child parent relation/	—
8	((parent* or mother* or father* or carer? or caregiver?) adj3 "mental health" adj (problem* or condition* or disorder* or illness* or difficult*)).ti,ab.	—
9	((parent* or mother* or father* or carer? or caregiver?) adj3 (mental* adj ill*)).ti,ab.	—
10	((parent* or mother* or father* or carer? or caregiver?) adj3 (depressi* or anxiety) adj3 (clinical or severe or major or chronic* or illness* or condition* or disorder* or difficult*)).ti,ab.	—
11	((parent* or mother* or father* or carer? or caregiver?) adj3 depression).ti,ab.	—
12	((parent* or mother* or father* or carer? or caregiver?) adj3 (suicidal or suicide)).ti,ab.	—
13	((parent* or mother* or father* or carer or caregiver) adj3 (mental* adj disorder*)).ti,ab.	—
14	((parent* or mother* or father* or carer or caregiver) adj3 (psychiatric or psychologic*) adj3 (illness* or condition* or disorder* or difficult*)).ti,ab.	—
15	7 or 8 or 9 or 10 or 11 or 12 or 13 or 14	—
16	((parent* or mother* or father* or carer* or caregiver* or sibling* or "family member" or brother* or sister*) adj3 (incarcerat* or prison* or "imprisoned" or "imprisonment" or jail* or gaol* or "penitentiary" or criminal* or "detention" or "probation" or "parole" or "young offender" or "young offenders")).ti,ab.	Corrected typos: 'probation' and 'penitentiary' Added: 'gaol'
17	("children of" adj2 prisoners).ti,ab.	—
18	((parent* or mother* or father* or carer* or caregiver* or sibling* or "family member" or brother* or sister*) adj2 (criminal* adj1 convict*)).ti,ab.	—
19	(child parent relation/ or child welfare/) and (Prisoner/ or Prison/)	—
20	16 or 17 or 18 or 19	—
21	((parent* or mother* or father* or carer? or caregiver?) adj3 (substance? or drug? or drinking or alcohol* or solvent? or medication?) adj2 ("use" or abus* or misuse* or addict* or disorder* or dependen*)).ti,ab.	—
22	((parent* or mother* or father* or carer? or caregiver?) adj3 (alcoholism or alcoholic* or "heavy drinking" or addicts or "heavy drinkers" or "substance related" or "substance affected" or (drinking adj1 problem*))).ti,ab.	—

23	(drug dependence/ or drug abuse/ or alcoholism/ or addiction/ or alcohol abuse/ or substance abuse/) and (child parent relation/ or child welfare/)	—
24	21 or 22 or 23	—
25	("Domestic violence" or "intimate partner violence" or ("IPV" not (vaccin* or ventilat*)) or "intimate partner abuse" or (battered adj3 (mother* or father* or spouse or partner)) or "domestic abuse" or "partner abuse" or (family adj2 violen*) or (families adj2 violen*)).ti,ab.	—
26	exp domestic violence/	—
27	25 or 26	—
28	((Sexual or physical* or verbal* or emotional* or psychologic*) adj2 (Abus* or assault*)) or incest* or "sexual violence" or ((rape or raped or violence) adj4 (home or family or parent* or families or homes or household?))).ti,ab.	—
29	Exposure to Violence/	—
30	(abus* or assault*).ti,ab.	—
31	((Ill adj treat*) or "Ill treatment" or maltreat* or mistreat* or "Neglect" or "cruelty" or "cruel" or abus* or assault*) adj3 ("offspring" or "young people" or children* or "childhood" or "child" or "boys" or "girls" or adolescen* or youth* or "young person" or teen* or preadolescen* or "early life").ti,ab.	—
32	maternal deprivation/ or Paternal deprivation/	—
33	(victim* adj2 ("home" or "homes" or "family" or "families" or "household" or "households")).ti,ab.	—
34	Child Abuse/ or child abuse survivor/ or childhood sexual abuse survivor/ or child neglect/ or child sexual abuse/	—
35	"Child of Impaired Parents"/ or "Child, Foster"/ or "Child, Orphaned"/ or "Child, Adopted"/ or Homeless Youth/	—
36	(homeless* adj3 ("young people" or children* or childhood or child or boys or girls or adolescen* or youth* or "young person*" or teen*)).ti,ab.	—
37	((("Looked after" or foster* or "adoptive" or "in care") adj1 ("young people" or children* or childhood or child or boys or girls or adolescen* or youth* or "young person*" or teen*)).ti,ab.	—
38	((("moving" adj1 "care") or ("leaving" adj1 "care")) and ("young people" or children* or childhood or child or boys or girls or adolescen* or youth* or "young person" or teen*)).ti,ab.	—
39	"Foster Care"/ or child protection/	—
40	("care leaver?" or "residential child*" or ("child welfare" adj2 (service* or centre or centres or center or centers)) or ("child protection" adj2 (service* or center or centers or centre or centres))).ti,ab.	—
41	((("living in care" or "kinship care" or "foster care" or "adoption care" or "group home" or "group homes" or "out of home placement" or "out of home care" or "child placement" or "local authority care" or "state care" or "alternative care" or "kith and kin care" or "kinship care") and ("young people" or children* or childhood or child or boys or girls or adolescen* or youth* or "young person" or teen*)).ti,ab.	—
42	child/ or "child, preschool"/ or adolescent/ or childhood/	—
43	(offspring or "young people" or children* or childhood or child or boys or girls or adolescen* or youth* or "young person" or teen* or juvenile* or preadolescen* or "early life").ti,ab.	—
44	42 or 43	—
45	Caregiver/ or parent/ or parenting/ or exp father/ or exp mother/ or exp child parent relation/	—
46	("Parent" or "parents" or "mother" or "mothers" or "father" or "fathers" or "home" or "homes" or "household" or "households" or "family" or "primary carer" or "foster carer" or "guardian" or "guardians" or "grandparent" or "grandparents" or "relatives" or maternal* or paternal* or sibling* or grandfather* or grandmother* or caregiver* or carer? or "families").ti,ab.	—
47	45 or 46	—
48	("Stressful childhood experiences" or "adverse childhood events" or "adverse childhood experiences" or "traumatic childhood experiences" or "Stressful childhood experience" or "adverse childhood event" or "adverse childhood experience" or "traumatic childhood experience" or "adverse home environment" or "adverse home environments" or "adverse family environment" or "adverse family environments" or "stressful home environment" or	—

	"stressful home environments" or "stressful family environment" or "stressful family environments").ti,ab.	
49	((child* or "young people*" or adolesc*) and (abus* or neglect)).jx.	_
50	(abus* or neglect).jx.	_
51	3 or 6 or 15 or 20 or 24 or 27 or 28 or 29 or 32 or 33 or 50	_
52	44 and 51	_
53	30 and 44 and 47	_
54	31 or 34 or 35 or 36 or 37 or 38 or 39 or 40 or 41 or 48	_
55	52 or 53 or 54	_
56	((("synthesis" or "systematic") and ("evidence" or "research" or "review")) or ("review" and (integrat* or critical* or "mapping" or "comprehensive" or "evidence" or "research" or "literature"))).ti. or ((systematic adj2 review*) or ("meta-analysis" or "Review articles" or "systematic review*" or "Overview of reviews" or "Review of Reviews") or ("data synthesis" or "evidence synthesis" or "metasynthesis" or "meta-synthesis" or "narrative synthesis" or "qualitative synthesis" or "quantitative synthesis" or "realist synthesis" or "research synthesis" or "synthesis of evidence" or "thematic synthesis" or "systematic map*" or "metaanaly*" or "meta-analy*" or "systematic overview*" or "systematic review*" or "systematically review*" or "bibliographic search" or "database search" or "electronic search" or "handsearch*" or "hand search*" or "keyword search" or "literature search" or "search term*" or "literature review" or "overview of reviews" or "review literature" or "reviewed the literature" or "reviews studies" or "scoping stud*" or "overview study" or "meta-ethnograph*" or "meta-epidemiological" or "data extraction" or "meta-regression" or "narrative review" or "art review" or "scoping review" or "iterative review" or "meta-summary")).ti,ab.	_
57	49 or 55	_
58	limit 57 to (meta analysis or "systematic review")	_
59	56 and 57	_
60	58 or 59	_
61	limit 60 to yr="2018 -Current"	Changed 2007 to 2018
62	_	Deleted line: 'limit 61 to english'

9.3.3 Appendix C.3 – Modified and annotated AMSTAR 2 tool

AMSTAR 2: a critical appraisal tool for systematic reviews that include randomised or non-randomised studies of healthcare interventions, or both

1. Did the research questions and inclusion criteria for the review include the components of PICO?

For Yes:

- ☐ Population
- ☐ Intervention
- ☐ Comparator group
- ☐ Outcome

Optional (recommended):

- ☐ Timeframe for follow-up

☐ Yes
☐ No

2. Did the report of the review contain an explicit statement that the review methods were established prior to the conduct of the review and did the report justify any significant deviations from the protocol?

For Partial Yes:
The authors state that they had a written protocol or guide that included ALL the following:

- ☐ review question(s)
- ☐ a search strategy
- ☐ inclusion/exclusion criteria
- ☐ a risk of bias assessment

For Yes:
As for partial yes, plus the protocol should be registered and should also have specified:

- ☐ a meta-analysis/synthesis plan, if appropriate, and
- ☐ a plan for investigating causes of heterogeneity
- ☐ justification for any deviations from the protocol

☐ Yes
☐ Partial Yes
☐ No

3. Did the review authors explain their selection of the study designs for inclusion in the review?

For Yes, the review should satisfy ONE of the following:

- ☐ Explanation for including only RCTs
- ☐ OR Explanation for including only NRSI
- ☐ OR Explanation for including both RCTs and NRSI

☐ Yes
☐ No

4. Did the review authors use a comprehensive literature search strategy?

For Partial Yes (all the following):

- ☐ searched at least 2 databases (relevant to research question)
- ☐ provided key word and/or search strategy
- ☐ justified publication restrictions (e.g. language)

For Yes, should also have (all the following):

- ☐ searched the reference lists / bibliographies of included studies
- ☐ searched trial/study registries
- ☐ included/consulted content experts in the field
- ☐ where relevant, searched for grey literature
- ☐ conducted search within 24 months of completion of the review

☐ Yes
☐ Partial Yes
☐ No

5. Did the review authors perform study selection in duplicate?

For Yes, either ONE of the following:

- ☐ at least two reviewers independently agreed on selection of eligible studies and achieved consensus on which studies to include
- ☐ OR two reviewers selected a sample of eligible studies and achieved good agreement (at least 80 percent), with the remainder selected by one reviewer.

☐ Yes
☐ No

Ignore timeframe

Guidance says this should be in the Intro, Methods or Abstract (so score shouldn't come from Results section)

Each element of PICO should be there though may not spell out acronym. Shouldn't have to read too much between the lines though.

Comparator is the part that's most often missed. To score Yes, they need to describe/mention what they're comparing to or say there's no comparison group. If they say RCT design was used, we take this a...

For Partial, they have to have all 4 in protocol. If there's no protocol, they get a No

Guidance says this can be anywhere in report, so it's fine for it to be in Limitations/ Discussion section. Also says you may need to read closely/infer. We'll follow gui...

We agreed more lenient criteria - For full Yes, for Qu 4, has to have 2 of the extras from the 'all the following list'

For Partial Yes, don't need to justify restrictions. They can still get a full Yes by doing 2 from Partial list and 2 from full list.

Our decision: % doesn't need to be specified. It's ideal but not essential that authors say good agreement. (Rationale: percentage is somewhat arbitrary e.g. Cohen's d inter-rater reliability can be hig...

If the paper says data extraction was done singly, but checked by a second person, we will accept this as equivalently rigorous t...

Be lenient - with qualitative work, can't data extract and establish a % agreement so be lenient here. It's ideal but not essential that authors say good agreement in extraction. Can give benefit of the doubt if other evidence of good method e.g. good...

We've adapted this one:

For Partial Yes - need to give something like the number of excluded e.g. in PRISMA flow chart or results (but not necessary to give full list of citations because there could be hundreds of papers).

For full Yes - give a brief header of why excluded e.g. in flow chart, say 'X number excluded because of study type, Y for po...

For Partial Yes, need to include all except comparison (i.e. comparison may be missing as it's not appropriate to have a c...

We'll be more lenient - For full Yes, if they state some detail for at least 2 of the following it's fine (Rationale: some studie...

Qu 9: key question for interpretation according to authors, particularly for NRSI.

"Review authors should have used a systematic approach to ROB assessment, preferably with a properly developed rating instrument...Several ROB instruments (for individual studies) are in common use, including the Newcastle Ottawa Scale, SIGN, and the Mixed Methods Appraisal Tool (MMAT). The most comprehensive assessment instrument is the recently introduced Cochrane instrument, ROBINS-I"

"Whatever instrument was used by the review authors, appraisers should be sati...

Given it's an important question, we'll be strict on this one and follow the AMSTAR 2 guidance as stated.

If a study has both RCT and Non-RCT, for a full Yes they need full Yes in both types of study and if it's less than that it's a Partial Yes overall. If no to both types of study, score No, otherwise Partial Yes if they pa...

This question has clear guidance and we won't deviate from it.

"Several investigations have shown that commercially sponsored studies are more likely to have findings that favour a sponsor's product than independently funded studies. It is valuable for review authors to document the funding sources for each study included in the review or to record that the information was not provided in the study reports. Depending on this information it may be possible to analyse separately the results from com...

AMSTAR 2: a critical appraisal tool for systematic reviews that include randomised or non-randomised studies of healthcare interventions, or both

6. Did the review authors perform data extraction in duplicate? For Yes, either ONE of the following: ☐ at least two reviewers achieved consensus on which data to extract from included studies ☐ OR two reviewers extracted data from a sample of eligible studies and achieved good agreement (at least 80 percent), with the remainder extracted by one reviewer.			☐ Yes ☐ No	
7. Did the review authors provide a list of excluded studies and justify the exclusions? For Partial Yes: ☐ provided a list of all potentially relevant studies that were read in full-text form but excluded from the review			For Yes, must also have: ☐ Justified the exclusion from the review of each potentially relevant study ☐ Yes ☐ Partial Yes ☐ No	
8. Did the review authors describe the included studies in adequate detail? For Partial Yes (ALL the following): ☐ described populations ☐ described interventions ☐ described comparators ☐ described outcomes ☐ described research designs			For Yes, should also have ALL the following: ☐ described population in detail ☐ described intervention in detail (including doses where relevant) ☐ described comparator in detail (including doses where relevant) ☐ described study's setting ☐ timeframe for follow-up ☐ Yes ☐ Partial Yes ☐ No	
9. Did the review authors use a satisfactory technique for assessing the risk of bias (RoB) in individual studies that were included in the review?				
RCTs For Partial Yes, must have assessed RoB from: ☐ unconcealed allocation, and ☐ lack of blinding of patients and assessors when assessing outcomes (unnecessary for objective outcomes such as all-cause mortality)		For Yes, must also have assessed RoB from: ☐ allocation sequence that was not truly random, and ☐ selection of the reported result from among multiple measurements or analyses of a specified outcome ☐ Yes ☐ Partial Yes ☐ No ☐ Includes only NRSI		
NRSI For Partial Yes, must have assessed RoB: ☐ from confounding, and ☐ from selection bias		For Yes, must also have assessed RoB: ☐ methods used to ascertain exposures and outcomes, and ☐ selection of the reported result from among multiple measurements or analyses of a specified outcome ☐ Yes ☐ Partial Yes ☐ No ☐ Includes only RCTs		
10. Did the review authors report on the sources of funding for the studies included in the review? For Yes: ☐ Must have reported on the sources of funding for individual studies included in the review. Note: Reporting that the reviewers looked for this information but it was not reported by study authors also qualifies				☐ Yes ☐ No

Be strict with this question as meta-analysis evidence is seen as good evidence so we want them to satisfy all criteria.

Where it says appropriate techniques, we...
Follow AMSTAR-2 guidance and be strict on it

For qu 12 and 13, they can't get a Y if they haven't performed a quality assessment/ RoB. E.g. for 13, if they just generically say low quality studies may affect results, we wouldn't credit this as being discussion of implications of RoB on results, because they're alluding to 'rob' but not 'RoB' i.e. not systematic assessment of Risk of Bias but more like generic acknowledgement of bias.

So for the majority of cases (though not all), authors won't be able to have a No for Qu9 of whether RoB was performed and then a Yes in Qu 12 or 13. The only exceptions might be where they scored a No for Qu 9 because they performed RoB but the tool they used didn't assess the required item...

For qu 12 and 13, they can't get a Y if they haven't performed a quality assessment/ RoB. E.g. for 13, if they just generically say low quality studies may affect results, we wouldn't credit this as being discussion of implications of RoB on results, because they're alluding to 'rob' but not 'RoB' i.e. not systematic assessment of Risk of Bias but more like generic acknowledgement of bias.

So for the majority of cases (though not all), authors won't be able to have a No for Qu9 of whether RoB was performed and then a Yes in Qu 12 or 13. The only exceptions might be where they scored a No for Qu 9 because they performed RoB but the tool they used didn't assess the required item...

Be more lenient on this one and read really closely for any implied discussion of this (will double check one another's answers for this one as it's easy to miss details). If they can't perform measure of heterogeneity because it's qualitative, that's fine. They should just acknowledge heterogeneity and/or its impact (or imply t...

Was heterogeneity looked at in Results?

AMSTAR 2: a critical appraisal tool for systematic reviews that include randomised or non-randomised studies of healthcare interventions, or both

11. If meta-analysis was performed did the review authors use appropriate methods for statistical combination of results?	
RCTs	
For Yes:	
☐ The authors justified combining the data in a meta-analysis	☐ Yes
☐ AND they used an appropriate weighted technique to combine study results and adjusted for heterogeneity if present.	☐ No
☐ AND investigated the causes of any heterogeneity	☐ No meta-analysis conducted
For NRSI	
For Yes:	
☐ The authors justified combining the data in a meta-analysis	☐ Yes
☐ AND they used an appropriate weighted technique to combine study results, adjusting for heterogeneity if present	☐ No
☐ AND they statistically combined effect estimates from NRSI that were adjusted for confounding, rather than combining raw data, or justified combining raw data when adjusted effect estimates were not available	☐ No meta-analysis conducted
☐ AND they reported separate summary estimates for RCTs and NRSI separately when both were included in the review	
12. If meta-analysis was performed, did the review authors assess the potential impact of RoB in individual studies on the results of the meta-analysis or other evidence synthesis?	
For Yes:	
☐ included only low risk of bias RCTs	☐ Yes
☐ OR, if the pooled estimate was based on RCTs and/or NRSI at variable RoB, the authors performed analyses to investigate possible impact of RoB on summary estimates of effect	☐ No
	☐ No meta-analysis conducted
13. Did the review authors account for RoB in individual studies when interpreting/ discussing the results of the review?	
For Yes:	
☐ included only low risk of bias RCTs	☐ Yes
☐ OR, if RCTs with moderate or high RoB, or NRSI were included the review provided a discussion of the likely impact of RoB on the results	☐ No
14. Did the review authors provide a satisfactory explanation for, and discussion of, any heterogeneity observed in the results of the review?	
For Yes:	
☐ There was no significant heterogeneity in the results	☐ Yes
☐ OR if heterogeneity was present the authors performed an investigation of sources of any heterogeneity in the results and discussed the impact of this on the results of the review	☐ No
15. If they performed quantitative synthesis did the review authors carry out an adequate investigation of publication bias (small study bias) and discuss its likely impact on the results of the review?	
For Yes:	
☐ performed graphical or statistical tests for publication bias and discussed the likelihood and magnitude of impact of publication bias	☐ Yes
	☐ No
	☐ No meta-analysis conducted

AMSTAR 2: a critical appraisal tool for systematic reviews that include randomised or non-randomised studies of healthcare interventions, or both

16. Did the review authors report any potential sources of conflict of interest, including any funding they received for conducting the review?

For Yes:

☐ The authors reported no competing interests OR

☐ The authors described their funding sources and how they managed potential conflicts of interest

☐ Yes

☐ No

To cite this tool: Shea BJ, Reeves BC, Wells G, Thuku M, Hamel C, Moran J, Moher D, Tugwell P, Welch V, Kristjansson E, Henry DA. AMSTAR 2: a critical appraisal tool for systematic reviews that include randomised or non-randomised studies of healthcare interventions, or both. *BMJ*. 2017 Sep 21;358:j4008.

9.3.4 Appendix C.4 – Additional results tables

Table 62: Information about ACE exposure (Abuse and Neglect)

Reference	Additional details about ACE(s) (inc. the presence of multiple ACEs)*
Physical Abuse	
Montgomery, Gardner & Bjornstad (2009)	Exposure to physical abuse.
Sexual Abuse	
Herbert & Bromfield (2016)	Exposure to sexual abuse predominantly. Also physical abuse and unspecified abuse.
Indrayani et al. (2020)	Exposure to sexual abuse.
Emotional Abuse	
Schrader McMillan et al. (2008)	Exposure to emotional abuse.
Domestic Violence	
Howarth et al. (2016) – chapters 3 & 5	Exposure to domestic violence and abuse (DVA).
Howarth et al. (2016) – chapter 7	Exposure to domestic violence and abuse (DVA).
Rizo et al. (2011)	Exposure to intimate partner violence (IPV).
Maltreatment (mixed)	
Goldman Fraser et al. (2013)	Exposure to maltreatment (abuse and/or neglect) and involvement with child protective services (CPS).
Gutterswijk et al. (2020)	Predominantly family dysfunction with aversive child-rearing practices and inadequate parenting. Following these exposures, all young people had also been placed in non-residential or residential care (i.e. intensive mental health intervention for severe emotional and/or behavioural problems).
Kanine et al. (2015)	Exposure to various forms of maltreatment. These exposures specifically consisted of: physical abuse; family domestic violence; family substance abuse; sexual abuse; neglect; and being deemed at-risk due to the maltreatment of siblings.
Lindstrom Johnson et al. (2018)	Exposure to violence (and the associated violence-related trauma). Exposures in each study included: intimate partner violence (IPV) or family conflict (52%); child maltreatment such as sexual or physical abuse and neglect (48%); PTSD as the result of multiple types of violence exposure (19%); community violence (10%).
Silverman et al. (2008)	Exposure to a mixture of traumatic events (predominantly involving some form of maltreatment or violence). These exposures specifically consisted of: sexual abuse; violence; physical abuse; neglect; marital violence; motor vehicle accidents; hurricanes and single-event traumas.
Waechter & Wekerle (2015)	Exposure to various forms of maltreatment (including sexual abuse and undefined ACEs). Also experiences of foster care in some cases.

* Information on additional ACEs as specified in the original paper. Other ACEs may have been experienced by participants but not noted.

Table 63: Information about ACE exposure (Unstable Housing)

Reference	Additional details about ACE(s) (inc. the presence of multiple ACEs)*
Homelessness	
Altena, Brilleslijper-Kater & Wolf (2010)	Experience of homelessness. Many have also experienced additional ACEs (both before and after becoming homeless), including: family conflict; physical abuse; emotional abuse; and sexual abuse.
Bassuk et al. (2014)	Experience of family homelessness specifically. Many have also experienced additional ACEs, including: a history of domestic violence; and household substance misuse.
Coren et al. (2016)	Experience of homelessness (including 'street-connected children' and 'runaway adolescents' who use substances/alcohol). Though not a homogenous group, many have also experienced additional ACEs and risks (both before and after becoming homeless), including: physical, psychological, sexual and economic exploitation; violence; social exclusion; lack of education or skills-based employment; coercion and control by adult gangs; criminality; substance misuse and addiction; and health issues such as HIV infection.
Morton et al. (2020)	Experience of homelessness. Many have also experienced additional ACEs, including violence.
Noh (2018)	Experience of homelessness (including children described as 'runaways'). Many have also experienced additional ACEs (both before and after becoming homeless), including: abuse; neglect; family violence; and parental alcohol problems.
Slesnick et al. (2009)	Experience of homelessness and unstable housing (including 'runaway youth', and those living on the streets, squatting, sofa-surfing, or in housing shelters). Many have also experienced additional ACEs (both before and after becoming homeless), including: family conflict; physical abuse; sexual abuse; neglect and parental unwillingness or inability to provide care.
Displacement and Being a Refugee	
Mitra & Hodes (2019)	Being an Unaccompanied Refugee Minor (URM) (i.e. experiencing unstable housing). Many have also experienced additional ACEs and traumas (both before and after their URM status), including: forcible displacement; persecution; conflict; violence; human rights violations; abuse; exploitation; loss of family members; and foster care (upon arrival to settling country).
O'Higgins, Ott & Shea (2018)	Being an Unaccompanied Refugee Minor (URM) (i.e. experiencing unstable housing). Many have also experienced additional ACEs and traumas (both before and after their URM status), including: violence; war; forcible displacement; trafficking; and foster care (upon arrival to settling country).
Piegenschke, Sihorsch & Christiansen (2019)	Unstable housing, specifically displacement (both internally and externally to home country; focuses on accompanied refugee minors (ARM) and displaced young people). Many have also experienced additional ACEs and traumas (both before and after fleeing), including: war; parental mental health problems; family violence; inappropriate housing conditions; and unspecified trauma exposure.
Williamson et al. (2017)	Being an Unaccompanied and Separated Child (UASC) in humanitarian crises. Many have also experienced additional ACEs and traumas (both before and after their UASC status), including: war; abuse; exploitation; violence; neglect; and foster care (upon arrival to settling country).

* Information on additional ACEs as specified in the original paper. Other ACEs may have been experienced by participants but not noted.

Table 64: Information about ACE exposure (Household Adversity)

Reference	Additional details about ACE(s) (inc. the presence of multiple ACEs)*
Parent or Guardian Mental Health Problems	
Barlow et al. (2015)	A mixture of ACE exposures, as well as other presentations, including: maternal depression; maltreating parents; incarcerated mother-infant dyads; parents experiencing a range of infant problems; mothers with concerns about their own role as mothers, wellbeing of the infants, or the mother-infant relationship; and parents of infants at risk of anxious attachment because their mothers were emotionally unavailable.
Bee et al. (2014) – <i>chapter 4</i>	Parental mental health problems. Specifically, severe parental mental illness in <i>Chapter 4</i> .
Bee et al. (2014) – <i>chapter 5</i>	Parental mental health problems. Specifically, depression in <i>Chapter 5</i> .
Beresford et al. (2008)	Parental mental health problems (or risk of them), including: serious mental illness (SMI); depression; psychotic disorder; bipolar; schizophrenia; and mixed or unspecified mental health problems.
Chen et al. (2021)	Parental schizophrenia.
Cuijpers et al. (2015)	Maternal depression.
Gunlicks & Weissman (2008)	Parental depression.
Havinga et al. (2021)	Parental mental health problems, specifically: mood disorders (depression or bipolar disorder) and/or anxiety disorders. Studies with general mental health problems were not considered.
Leijten et al. (2019)	Parental depression; the focus of the paper was maternal depression specifically.
Letourneau et al. (2017)	Maternal (perinatal) depression, both antenatal and postpartum.
Loechner et al. (2018)	Parental depression.
Marie-Mitchell & Kostolansky (2019)	A mixture of ACE exposures, specifically: parental mental health problems/depression (16 studies); parental drug or alcohol misuse (15 studies); and domestic violence (12 studies).
Newton et al. (2020)	Maternal (perinatal) mental health problems.
Oja et al. (2020)	Parental mental health problems (including depression and major depression, anxiety, and bipolar), substance misuse, and the death of a parent in some cases. Other parental health problems outside the scope of our review included HIV and terminal cancer (though some children experienced parental bereavement by cancer which was within our scope).
Poobalan et al. (2007)	Maternal (postpartum) depression which had been diagnosed. Interventions for mothers with maternity 'blues', maternal psychosis or at risk for mental health problems were excluded.
Rayce et al. (2020)	Maternal (antenatal and postpartum) depressive symptoms (identified through a screening tool; not necessarily fulfilling diagnostic criteria). Of note, parents with severe mental health problems such as schizophrenia were excluded.
Reupert et al. (2012)	Parental mental health problems, excluding substance misuse. Mental health problems included: anxiety; depression and major depression; affective disorders; serious mental illness (SMI).

Siegenthaler, Munder & Egger (2012)	Parental mental health problems, consisting of: depression, anxiety and/or affective disorders; alcohol dependence; and drug dependence.
Thanhäuser et al. (2017)	Parental mental health problems, consisting of: depression and/or anxiety; substance use disorders; eating disorders; and mixed disorders. In 78% of the cases, the parent with the mental health problem was the mother.
<i>Parent or Guardian Substance Misuse</i>	
Ahern et al. (2021)	Parental substance use disorders (SUDs)/opiate use disorders (OUDs).
Broning et al. (2012)	Parental alcohol or substance misuse.
Calhoun et al. (2015)	Parental substance misuse. Other ACEs included: maltreatment; neglect; child protective services involvement; and parental imprisonment.
Niccols et al. (2012)	Maternal substance misuse. Some have also experienced other ACEs, including: parental mental health problems; domestic violence (perpetrated against mother); maltreatment; abuse; neglect; and associated involvement with child protective services (CPS).
Phillips, Gleeson & Waites-Garrett (2009)	Parental substance misuse and involvement with the criminal justice system (including being imprisoned or on probation).
Ruff et al. (2010)	Parental alcohol or substance misuse. Some also experienced or witnessed intimate partner violence (IPV).
<i>Parental Imprisonment or Probation</i>	
Nilsen et al. (2015)	Parental imprisonment.
Troy et al. (2018)	Parental imprisonment (28 articles) or recent release from prison or on community custody order (1 article). Also an increased likelihood of exposure to the following difficulties: parental mental health problems; parental substance misuse; difficult interpersonal relationships; and harsh parenting.
<i>Parental Separation or Divorce</i>	
Poli et al. (2017)	Parental separation or divorce.
Templer et al. (2017)	Parental separation or divorce (this is the implied ACE given the paper's focus on parental alienation, where one parent alienates another, seemingly when separated or divorced).
<i>Bereavement</i>	
Bergman, Axberg & Hanson (2017)	Death of a parent or significant caregiver.
Chen & Panebianco (2018)	Death of a family member (parent, sibling, or unspecified family member or loved one).
De López, Søndergaard Knudsen & Hansen (2020)	Death of a parent or sibling.
Journot-Reverbel et al. (2017)	Death of a close relative (parent or sibling) by suicide.

* Information on additional ACEs as specified in the original paper. Other ACEs may have been experienced by participants but not noted.

Table 65: Information about ACE exposure (Involvement with Child Protective Services (CPS) or Living in Care)

Reference	Additional details about ACE(s) (inc. the presence of multiple ACEs)*
<i>Involvement with Child Protective Services (CPS) or Living in Care</i>	
Bailey et al. (2018)	Out-of-home care (OoHC), often preceded by other ACEs, including: physical, sexual or emotional abuse; neglect; and domestic violence.
Bergström et al. (2020)	Foster family care/out-of-home care (OoHC). Though not specified in the paper, this would generally be preceded by other ACEs.
Everson-Hock et al. (2011)	Looked-after children (LAC). Though not specified in the paper, this would generally be preceded by other ACEs.
Everson-Hock et al. (2012)	Looked-after children (LAC). Though not specified in the paper, this would generally be preceded by other ACEs.
Galvin et al. (2021)	Residential out-of-home care (OoHC), often preceded by other ACEs, including: neglect; and abuse including sexual abuse.
Grube & Liming (2018)	Involvement with the child welfare system. Children lived with either foster parents (6 studies) or biological parents, involved in a foster-care diversion programme (4 studies). In these 10 studies, involvement with the child welfare system was often preceded by other ACEs or challenges, for example: one study included homeless children and families; some of the children involved in the child welfare diversion programme were referred after some kind of maltreatment; one study sampled children living with foster caregivers and experiencing attachment-related disorders; and one study and its two follow-up studies sampled children who were living with foster caregivers after being removed from their home.
Hambrick et al. (2016)	Foster care, often preceded by other ACEs, including: abuse; neglect; domestic violence; community violence; disruption to primary attachment relationships; and in-utero exposure to drugs and alcohol.
Heerde et al. (2018)	Out-of-home care (OoHC). Separation or removal from a child's family of origin by child protection authorities is often preceded by other ACEs, including: abuse; neglect; and family breakdown.
Hermenau et al. (2017)	Institutional care for orphans, often preceded or followed by other ACEs, including: maltreatment; unspecified trauma; death of parent(s); and violence.
James, Alemi & Zepeda (2013)	Residential care, specifically short- or long-term group homes or residential treatment centres, often preceded by maltreatment or other ACEs.
Kemmis-Riggs, Dickes & McAloon (2018)	Foster care and kinship care, often preceded by other ACEs or complex trauma, including: maltreatment (physical, emotional or sexual abuse and/or neglect); traumatic loss and/or related experiences of maltreatment such as prenatal exposure to drug and alcohol use and disrupted attachment with primary caregiver.
Kerr & Cossar (2014)	Foster care and/or adoption, often preceded by other ACEs, including: abuse and/or neglect within the family of origin.
Kinsey & Schlösser (2013)	Foster care and kinship care, often preceded by other ACEs, including: abuse; neglect; and family dysfunction. In some cases, however, foster care placement is not due to ACEs, but is instead to provide short-term respite for parents caring for a child with disabilities.
Liabo, Gray & Mulcahy (2013)	Looked-after children (LAC). Being in the child welfare system is often preceded by other ACEs, including: abuse; and neglect.
Maclean et al. (2016)	Out-of-home care (OoHC) or in-home care, preceded by maltreatment.
Marcellus et al. (2021)	Foster care and exposure to prenatal substance misuse. Other ACEs experienced by some of the young people included: neglect; and maltreatment.

Roberts et al. (2016)	Looked-after children (LAC). Being in the child welfare system is often preceded by other ACEs and challenges, including: unspecified trauma; separation; loss; difficult birth family relationships; and issues with attachment relationships.
SBU Assessments (2017)	Foster care, often preceded by maltreatment or other ACEs.
Schoemaker et al. (2020)	Foster care and/or adoption, often preceded by other ACEs and challenges, including: abuse and/or neglect; and separation from family of origin.
Solomon, Niec & Schoonover (2017)	Foster care, often preceded by other ACEs, including: abuse; and neglect.
Turner, Macdonald & Dennis (2007)	Looked-after children (LAC) and those with foster carers, often preceded by other ACEs, including: unspecified maltreatment; physical or sexual abuse; and neglect.
Uretsky & Hoffman (2017)	Foster care. Though not specified in the paper, this would generally be preceded by other ACEs.
Van Andel et al. (2014)	Foster care, often preceded by other ACEs and challenges, including: hostile home environment; abuse; neglect; and attachment issues.
Wilson & Barnett (2020)	Out-of-home care (OoHC), preceded by other ACEs. The focus of the paper was children whose primary condition for admission to care was abuse, neglect or parental incapacity.
Winokur, Holtan & Batchelder (2014)	Kinship care or foster care (with the latter as a comparison intervention for the former). Removal from a child's family of origin by child protection authorities is often preceded by other ACEs, including: abuse; neglect; and maltreatment (including physical abuse, sexual abuse, psychological maltreatment, abandonment, threats of harm, and/or caregiver drug addiction).
Winokur, Holtan & Batchelder (2018)	Kinship care or foster care (with the latter as a comparison intervention for the former). Removal from a child's family of origin by child protection authorities is often preceded by other ACEs, including: abuse; neglect; and maltreatment (including physical abuse, sexual abuse, psychological maltreatment, abandonment, threats of harm, and/or caregiver drug addiction).
Xu & Bright (2018)	Foster care, in the form of kinship care and non-kinship care, often preceded by maltreatment or other ACEs.
Ziviani et al. (2012)	Out-of-home care (OoHC), specifically involving young people with a disability. Being in the child welfare system is often preceded by other ACEs and challenges, including: abuse; neglect; difficulties associated with low family income; caregiver/parental substance misuse; caregiver/parental mental health problems; and family violence.

* Information on additional ACEs as specified in the original paper. Other ACEs may have been experienced by participants but not noted.

Table 66: Examples of cohort identification methods

Cohort identification method and examples	
Directly via young person	<i>Young people's service contact directly resulting from ACE exposure</i> - The ACE itself is synonymous with contact with services (specifically experience of out-of-home care and child welfare involvement), thus making young people identifiable for recruitment to interventions. For example: - Studies of experiences of foster care, foster carers, kinship care or out-of-home care (Bailey et al., 2018; Galvin et al., 2022; Kemmis-Riggs et al., 2018; Marcellus et al., 2021; SBU Assessments, 2017; Wilson & Barnett, 2020; Ziviani et al., 2012). - Some people were recruited at the start of initial foster care placement, and one study used a sample of fostered and adopted children recruited through self-selection of foster/adoptive parents or referral by a professional (Kerr & Cossar, 2014). - Children were involved with the child welfare system so were recruited to the ABC intervention; some were recruited as part of a foster-care diversion program. Others were living with foster caregivers and experiencing attachment-related disorders. The child welfare system was not the primary service sector making the referral to the ABC project; instead, these children were treatment-seeking, and the referral setting was described as a clinical-based setting (Grube & Liming, 2018). - Recruitment happened via residential youth care (a 24hr mental health intervention) (Gutterswijk et al., 2020). - Identification happens due to interactions with services or because the ACE itself (specifically homelessness) is visible to services. For example: - Young people were approached on the street or through residential services (see for example, Altena et al., 2010). - Recruited via community-based organisations (e.g. shelter, schools), as well as through direct recruitment (e.g. by flyers and word-of-mouth) (Coren et al., 2016). - All the studies recruited participants from community agencies that provided services for runaway and homeless youth, such as shelters and drop-in centres (Noh, 2018). - Young people were recruited via assisting shelters, emergency runaway shelters, and street or drop-in centres (Slesnick et al., 2009). - Co-location of sexual abuse services through the Child Advocacy Centre (CAC) model. The CAC model comprises multidisciplinary teams, joint investigations, and services, all within a single child-friendly environment. Through this model, the ACE (i.e. sexual abuse) is reported in the same place as intervention/support is offered (Herbert & Bromfield, 2016).
	<i>Young people's service contact not resulting from ACE exposure</i> - Infants were identified via paediatric clinics (Barlow et al., 2015). - Young girls who had been sexually abused and were at risk for depression as a result were identified by midwives (the paper was unclear about how midwives came into contact with these girls) (Indrayani et al., 2020).
	<i>Key transition periods</i>

	Young people were identified as at-risk at key transition periods, when leaving a service. For example, young people transitioning out of juvenile justice or out of foster care were identified as at increased risk for homelessness, so prevention efforts were focused here (Morton et al., 2020).
	Screening programmes or tools for young people
	- Universal homelessness screening, as exemplified in The Geelong Project (TGP) in Australia. A coordinated homelessness prevention model in schools and community organisations involving universal screening for students at risk for homelessness, followed by tailored case management and support (Morton et al., 2020). - During home visits at 12 months, the 'Strange Situation Procedure' (from Ainsworth, 1978) was used; interventions were offered to infants based on their attachment classification (Barlow et al., 2015).
	Data analytics The review included an evaluation of the Behaviour Analysis Services Programme (BASP), an intervention that used data analytics to identify runaway behaviours (Morton et al., 2020).
Indirectly via parent/caregiver	Parents' or caregivers' mental health status or contact with healthcare services
	- Parent(s) had a known mental health problem, so participants were identified for intervention based on this. For example: - Babies were recruited via mothers' involvement with mental health services; this was either preventive or reactive to emerging challenges. Recruitment was through liaison with services or being directly plugged into services. Recruitment sites also included delivery wards and mother and baby units (MBU) (Barlow et al., 2015). - Specialist interventions were delivered within perinatal mental health services (Newton et al., 2020). - All of the studies used a convenience sample of mothers with antenatal or postpartum depression. Mothers were recruited via: referrals from health professionals; media and community outreach programmes; university hospitals or outpatient clinics (Letourneau et al., 2017). - Most studies in the systematic review used multiple recruitment strategies. All but one study recruited people via mental health care services. This included: using databases from Health Maintenance Organization (HMO) databases; direct referrals from practitioners; letters to physicians and/or flyers in health clinics. In addition, some used recruitment strategies via media outlets (e.g. newspapers, radio, television, and internet postings) (Havinga et al., 2021). - Other studies of parental mental health problems (see for example, Bee et al., 2014; Loechner et al., 2018).
	Screening programmes or tools for parents or caregivers Maternal depressive symptoms were screened for using a questionnaire; mothers did not have to fulfil criteria for clinical depression. Some mothers were recruited from postpartum units in hospitals in the USA. Although not tested in their review, the authors suggested a future focus of research could be screening for depression in pregnancy and starting treatment before the birth of the baby (Rayce et al., 2020).
Multiple sources	Screening programmes or tools for parents and young people
	Assessment for parental substance misuse was conducted in a variety of ways, including self-report (i.e. questionnaires, interviews) of children, parents, or by a third party e.g. teacher, therapist, or medical practitioner (Bröning et al., 2012).

Table 67: Further detail on examples of modifications/tailoring, grouped by theme

Modification relates to...	Examples and citations discussing modifications/tailoring
Young people	With respect to modifications relating to young people themselves, the following themes were identified: • Sex: Teen Club, an intervention for children of parents with substance use disorder, was originally developed in 1992 for female adolescents, but was later extended to boys and girls (Ahern et al., 2020). • Age: ○ The ‘Children’s Programme Kit: Supportive Education for Children of Addicted Parents (CPK)’, an intervention for children of parents who misuse alcohol or substances, was broken into modules adapted with age-appropriate content for three age brackets, namely school-age, middle school-aged and high school-aged (Ahern et al., 2020). ○ The Attachment and Biobehavioural Catch-Up (ABC) intervention, originally developed for infants aged 6 to 24 months, has been adapted for children aged 24 to 28 months, though evaluation of effectiveness was still underway at the time the authors wrote their review, thus not included (Grube & Liming, 2018). • Cultural or ethnic background: ○ Teen Club was carried out with a sample of young people from ethnic minority backgrounds (specifically Black and Hispanic adolescents) and was described as taking steps towards a culturally sensitive intervention, including having multi-cultural facilitators (Ahern et al., 2020). ○ Some studies reported a benefit for mental health outcomes from young people being in foster placements with people from the same ethnic background as themselves (O’Higgins et al., 2018). ○ Wilson and Barnett suggested that the effectiveness of yoga in Indian orphanages may have partially been explained by the fact it fit with cultural and spiritual beliefs in India (Wilson & Barnett, 2020). • Specific ACE-exposure: ○ A history of trauma in young people in residential out-of-home care: Based on their findings, Galvin and colleagues (2021) recommended that interventions and practice models for young people in residential out-of-home care should incorporate trauma-informed care and psychoeducation, especially to prevent further traumas occurring. Trauma-informed elements helped young people to connect emotion and behaviours with past experiences; studies also included teaching prosocial behaviours and skill-building, such as communication skills, problem-solving, and goal-setting (Galvin et al., 2022). ○ Experiences of foster care: In some cases, interventions were adapted for the foster care context. Specifically, Incredible Years, Parent Child Interaction Therapy, and Trauma-Focused Cognitive Behavioural Therapy (IY, PCIT and TF-CBT respectively). For Incredible Years, the adaptations mainly consisted of adding information relevant to children in foster care to the session content. For Trauma-Focused Cognitive Behavioural Therapy, an engagement intervention was added, but other elements of the delivery remained unchanged (Hambrick et al., 2016). ○ Experiences of homelessness or unstable housing: Grube and Liming noted that the ABC intervention is meant to be delivered wherever the infant and their family resides; this includes shelters, hotels, and so on (Grube & Liming, 2018).

Parents and caregivers	Modifications relating to the parent(s) and caregivers included: • Fathers: Some interventions reported the involvement (to varying degrees) of infants' fathers in interventions, not just mothers, and all showed significant improvement (Newton et al., 2020). • Perpetration of abuse: Montgomery, Gardner and Bjornstad highlighted several interventions which had additional components designed to address the needs of abusive parents. For example, anger or stress management components (Montgomery et al., 2009). • Co-parenting: Another systematic review noted that the Incredible Years (IY) programme could be adapted to 'Incredible years + co-parent adaptation (IY + CP)'. This version was designed to deliver a joint training format to foster and biological parent pairs, with the intention of developing more collaborative parenting relationships between them (Kemmis-Riggs et al., 2018). • Parental alienation: When working with parental alienation, for example, in extreme cases after parental separation, Templar noted the necessity for systemic family therapy to be tailored specifically to the issue of parental alienation. Furthermore, they noted this specialised family therapy needs to be court ordered, and non-compliance with these orders needs to carry sanctions on the alienating parent (Templar et al., 2017).
Intervention and personnel	Modifications relating to the intervention and personnel included: • Staffing and training: ○ When Teen Club (for children of parents with substance misuse) was run with reduced involvement of nurse practitioners, the success of the intervention was negatively impacted (Ahern et al., 2020). ○ Though the curriculum resembled that of a typical preschool, therapeutic day treatment programmes with children who had experienced maltreatment were delivered by staff with more advanced training in child development and clinical issues (Kanine et al., 2015). • Flexibility and timing: ○ There was an example of case management for street-connected young people which purported to have increased flexibility in terms of timing and duration (Coren et al., 2016). ○ Separate components of the Incredible Years programme (as opposed to the full programme) were sometimes used, including parent management training, such as discipline and positive parenting techniques (Solomon et al., 2017). ○ Adaptations to timing included condensing an intervention, extending it, or only offering a portion of it (James et al., 2013).

Lack of modifications	Several of the systematic reviews did note that modification or targeting could be helpful, though was sometimes lacking. Areas for exploration included: • When considering homelessness, Morton and colleagues noted that certain subpopulations are at an increased risk for homelessness. They identified literature gaps in intervention tailoring for young people who were Black or Hispanic, identifying as LGBTQ, pregnant or parenting, or those living in rural communities (Morton et al., 2020). • More culturally-responsive services were identified as a potentially helpful avenue of exploration, especially because young people from a biracial background can be at higher risk for socioemotional problems compared to other racial groups, and are easily overlooked by child welfare services when discussing racial disparities. Moreover, they suggested that gender-specific interventions may be appropriate in some cases due to findings that girls had different behaviour changes over time compared to boys (Xu & Bright, 2018). • In the case of bereavement, de López and colleagues suggested modifications could cater for cultural sensitivity (e.g. religiosity, parental beliefs etc) and cause sensitivity (i.e. expected versus unexpected loss) to maximise the effectiveness of the grief treatment (de López et al., 2020). • Group-based behavioural couples therapy (BCT) instead of the current conjoint design was suggested as an area for exploration, not least as a way to manage cost and resource allocations (Ruff et al., 2010). • Homelessness interventions could be adapted for the developmental stage of young people, and also their specific reasons for running away or homelessness. Moreover, adaptations based on the 'homeless trajectory' could be made, aimed at increasing potential resources and protective factors available to young people and/or families (Slesnick et al., 2009). • In Troy and colleagues' systematic review of interventions for parents in the criminal justice system, programme materials for parents (manuals and handouts) were assessed for their appropriateness. Some materials were seen positively, whilst others were seen as 'too academic'. Participants who viewed material as too academic suggested that the inclusion of digital workbooks with practical exercises could help (Troy et al., 2018). • Howarth and colleagues found children exposed to domestic violence valued attending separate groups from their siblings; this could be a modification incorporated into future interventions (Howarth et al., 2016).

9.3.5 Appendix C.5 – References for 82 included papers

- Ahern, N. R., Mechling, B., Palumbo, R., & Woodard, E. (2020). Children of Parents With Opioid Use Disorder. *Journal of Psychosocial Nursing and Mental Health Services*, 59(3), 28–34. <https://doi.org/10.3928/02793695-20201203-03>
- Altena, A. M., Brilleslijper-Kater, S. N., & Wolf, J. L. M. (2010). Effective interventions for homeless youth: a systematic review. *American Journal of Preventive Medicine*, 38(6), 637–645. <https://doi.org/10.1016/j.amepre.2010.02.017>
- Bailey, C., Klas, A., Cox, R., Bergmeier, H., Avery, J., & Skouteris, H. (2018). Systematic review of organisation-wide, trauma-informed care models in out-of-home care (OoHC) settings. *Health & Social Care in the Community*, 27(3), e10–e22. <https://doi.org/10.1111/hsc.12621>
- Barlow, J., Bennett, C., Midgley, N., Larkin, S. K., & Wei, Y. (2015). Parent-infant psychotherapy for improving parental and infant mental health. *Cochrane Database of Systematic Reviews*, 1(1), 1–129. <https://doi.org/10.1002/14651858.CD010534.pub2>
- Bassuk, E. L., DeCandia, C. J., Tsertsvadze, A., & Richard, M. K. (2014). The effectiveness of housing interventions and housing and service interventions on ending family homelessness: a systematic review. *American Journal of Orthopsychiatry*, 84(5), 457–474. <https://doi.org/10.1037/ort0000020>
- Bee, P., Bower, P., Byford, S., Churchill, R., Calam, R., Stallard, P., ... Abel, K. (2014). The clinical effectiveness, cost-effectiveness and acceptability of community-based interventions aimed at improving or maintaining quality of life in children of parents with serious mental illness: a systematic review. *Health Technology Assessment*, 18(8), 1–250. <https://doi.org/https://dx.doi.org/10.3310/hta18080>
- Beresford, B., Clarke, S., Gridley, K., Parker, G., Pitman, R., Spiers, G., & Light, K. (2008). *Technical report for SCIE research review on access, acceptability and outcomes of services/interventions to support parents with mental health problems and their families*. Retrieved from <https://www.york.ac.uk/inst/spru/research/pdf/SCIEReview2.pdf>
- Bergman, A.-S., Axberg, U., & Hanson, E. (2017). When a parent dies – a systematic review of the effects of support programs for parentally bereaved children and their caregivers. *BMC Palliative Care*, 16(39), 1–15. <https://doi.org/10.1186/s12904-017-0223-y>
- Bergström, M., Cederblad, M., Håkansson, K., Jonsson, A. K., Munthe, C., Vinnerljung, B., ... Sundell, K. (2020). Interventions in Foster Family Care: A Systematic Review. *Research on Social Work Practice*, 30(1), 3–18. <https://doi.org/10.1177/1049731519832101>
- Bröning, S., Kumpfer, K., Kruse, K., Sack, P.-M., Schaunig-Busch, I., Ruths, S., ... Thomasius, R. (2012). Selective prevention programs for children from substance-affected families: a comprehensive systematic review. *Substance Abuse Treatment, Prevention, and Policy*, 7(23), 1–17. <https://doi.org/10.1186/1747-597X-7-23>
- Calhoun, S., Conner, E., Miller, M., & Messina, N. (2015). Improving the outcomes of children affected by parental substance abuse: a review of randomized controlled trials. *Substance Abuse & Rehabilitation*, 6, 15–24. <https://doi.org/10.2147/SAR.S46439>
- Chen, C. Y.-C., & Panebianco, A. (2018). Interventions for young bereaved children: A systematic review and implications for school mental health providers. *Child & Youth Care Forum*, 47(2), 151–171. <https://doi.org/10.1007/s10566-017-9426-x>
- Chen, J., Chen, X., Leung, S. S. M., & Tsang, H. W. H. (2021). Potential impacts, alleviating factors, and interventions for children of a parent with schizophrenia: A scoping review. *Children and Youth Services Review*, 120. <https://doi.org/10.1016/j.childyouth.2020.105751>
- Coren, E., Hossain, R., Pardo Pardo, J., & Bakker, B. (2016). Interventions for promoting reintegration and reducing harmful behaviour and lifestyles in street-connected children and young people. *Cochrane Database of Systematic Reviews*, (1), 1–126. <https://doi.org/10.1002/14651858.CD009823.pub3>
- Cuijpers, P., Weitz, E., Karyotaki, E., Garber, J., & Andersson, G. (2015). The effects of psychological treatment of maternal depression on children and parental functioning: a meta-analysis.

- European Child & Adolescent Psychiatry*, 24(2), 237–245. <https://doi.org/10.1007/s00787-014-0660-6>
- de López, K. J., Søndergaard Knudsen, H., & Hansen, T. G. B. (2020). What Is Measured in Bereavement Treatment for Children and Adolescents? A Systematic Literature Review. *Illness, Crisis, and Loss*, 28(4), 363–387. <https://doi.org/http://dx.doi.org/10.1177/1054137317741713>
- Everson-Hock, E. S., Jones, R., Guillaume, L., Clapton, J., Duenas, A., Goyder, E., ... Swann, C. (2011). Supporting the transition of looked-after young people to independent living: a systematic review of interventions and adult outcomes. *Child: Care, Health & Development*, 37(6), 767–779. <https://doi.org/10.1111/j.1365-2214.2011.01287.x>
- Everson-Hock, E. S., Jones, R., Guillaume, L., Clapton, J., Goyder, E., Chilcott, J., ... Swann, C. (2012). The effectiveness of training and support for carers and other professionals on the physical and emotional health and well-being of looked-after children and young people: a systematic review. *Child: Care, Health & Development*, 38(2), 162–174. <https://doi.org/10.1111/j.1365-2214.2011.01247.x>
- Fraser, J. G., Lloyd, S., Murphy, R., Crowson, M., Zolotor, A. J., Coker-Schwimmer, E., & Viswanathan, M. (2013). A comparative effectiveness review of parenting and trauma-focused interventions for children exposed to maltreatment. *Journal of Developmental and Behavioral Pediatrics*, 34(5), 353–368. <https://doi.org/10.1097/DBP.0b013e31828a7dfc>
- Galvin, E., O'Donnell, R., Breman, R., Avery, J., Mousa, A., Halfpenny, N., & Skouteris, H. (2022). Interventions and Practice Models for Improving Health and Psychosocial Outcomes for Children in Residential Out-of-Home Care: Systematic Review. *Australian Social Work*, 75(1), 33–47. <https://doi.org/10.1080/0312407X.2020.1856394>
- Grube, W. A., & Liming, K. W. (2018). Attachment and biobehavioral catch-up: A systematic review. *Infant Mental Health Journal*, 39(6), 656–673. <https://doi.org/10.1002/imhj.21745>
- Gunlicks, M. L., & Weissman, M. M. (2008). Change in child psychopathology with improvement in parental depression: a systematic review. *Journal of the American Academy of Child & Adolescent Psychiatry*, 47(4), 379–389. <https://doi.org/10.1097/CHI.0b013e3181640805>
- Gutterswijk, R. V., Kuiper, C. H. Z., Lautan, N., Kunst, E. G., van der Horst, F. C. P., Stams, G. J. J. M., & Prinzie, P. (2020). The outcome of non-residential youth care compared to residential youth care: A multilevel meta-analysis. *Children and Youth Services Review*, 113(104950), 1–11. <https://doi.org/10.1016/j.childyouth.2020.104950>
- Hambrick, E. P., Oppenheim-Weller, S., N'zi, A. M., & Taussig, H. N. (2016). Mental Health Interventions for Children in Foster Care: A Systematic Review. *Children and Youth Services Review*, 70, 65–77. <https://doi.org/10.1016/j.childyouth.2016.09.002>
- Havinga, P. J., Maciejewski, D. F., Hartman, C. A., Hillegers, M. H. J., Schoevers, R. A., & Penninx, B. W. J. H. (2021). Prevention programmes for children of parents with a mood/anxiety disorder: Systematic review of existing programmes and meta-analysis of their efficacy. *The British Journal of Clinical Psychology*, 60(2), 212–251. <https://doi.org/10.1111/bjc.12277>
- Heerde, J. A., Hemphill, S. A., & Scholes-Balog, K. E. (2018). The impact of transitional programmes on post-transition outcomes for youth leaving out-of-home care: a meta-analysis. *Health & Social Care in the Community*, 26(1), e15–e30. <https://doi.org/http://dx.doi.org/10.1111/hsc.12348>
- Herbert, J. L., & Bromfield, L. (2016). Evidence for the Efficacy of the Child Advocacy Center Model: A Systematic Review. *Trauma, Violence & Abuse*, 17(3), 341–357. <https://doi.org/10.1177/1524838015585319>
- Hermenau, K., Goessmann, K., Rygaard, N. P., Landolt, M. A., & Hecker, T. (2017). Fostering Child Development by Improving Care Quality: A Systematic Review of the Effectiveness of Structural Interventions and Caregiver Trainings in Institutional Care. *Trauma Violence & Abuse*, 18(5), 544–561. <https://doi.org/10.1177/1524838016641918>
- Howarth, E., Moore, T. H. M., Welton, N. J., Lewis, N., Stanley, N., MacMillan, H., ... Feder, G. (2016). IMPROving Outcomes for children exposed to domestic Violence (IMPROVE): an evidence

- synthesis. *Public Health Research*, 4(10), 1–378. <https://doi.org/10.3310/phr04100>
- Indrayani, T., Palutturi, S., Amiruddin, R., Bintara Birawida, A., Widowati, R., Rukmaini, R., & Owildan, W. B. (2020). The development of T-CBT model to improve the competence of midwives in prevention depression of sexual violence victims. *Indian Journal of Public Health Research and Development*, 11(2), 2607–2612. <https://doi.org/10.37506/v11/i2/2020/ijphrd/195224>
- James, S., Alemi, Q., & Zepeda, V. (2013). Effectiveness and implementation of evidence-based practices in residential care settings. *Children and Youth Services Review*, 35(4), 642–656. <https://doi.org/10.1016/j.childyouth.2013.01.007>
- Journot-Reverbel, K., Raynaud, J.-P., Bui, E., & Revet, A. (2017). Support groups for children and adolescents bereaved by suicide: Lots of interventions, little evidence. *Psychiatry Research*, 250, 253–255. <https://doi.org/10.1016/j.psychres.2017.01.077>
- Kanine, R. M., Tunno, A. M., Jackson, Y., & O'Connor, B. M. (2015). Therapeutic Day Treatment for Young Maltreated Children: A Systematic Literature Review. *Journal of Child and Adolescent Trauma*, 8, 187–199. <https://doi.org/10.1007/s40653-015-0053-0>
- Kemmis-Riggs, J., Dickes, A., & McAloon, J. (2018). Program Components of Psychosocial Interventions in Foster and Kinship Care: A Systematic Review. *Clinical Child and Family Psychology Review*, 21, 13–40. <https://doi.org/http://dx.doi.org/10.1007/s10567-017-0247-0>
- Kerr, L., & Cossar, J. (2014). Attachment Interventions with Foster and Adoptive Parents: A Systematic Review. *Child Abuse Review*, 23(6), 426–439. <https://doi.org/10.1002/car.2313>
- Kinsey, D., & Schlösser, A. (2013). Interventions in foster and kinship care: A systematic review. *Clinical Child Psychology & Psychiatry*, 18(3), 429–463. <https://doi.org/10.1177/1359104512458204>
- Leijten, P., Gardner, F., Melendez-Torres, G. J., Weeland, J., Hutchings, J., Landau, S., ... Scott, S. (2019). Co-occurring change in children's conduct problems and maternal depression: Latent class individual participant data meta-analysis of the Incredible Years parenting program. *Development and Psychopathology*, 31(5), 1851–1862. <https://doi.org/10.1017/S0954579419001068>
- Letourneau, N. L., Dennis, C., Cosic, N., & Linder, J. (2017). The effect of perinatal depression treatment for mothers on parenting and child development: A systematic review. *Depression and Anxiety*, 34(10), 928–966. <https://doi.org/10.1002/da.22687>
- Liabo, K., Gray, K., & Mulcahy, D. (2013). A systematic review of interventions to support looked-after children in school. *Child & Family Social Work*, 18(3), 341–353. <https://doi.org/10.1111/j.1365-2206.2012.00850.x>
- Lindstrom Johnson, S., Elam, K., Rogers, A. A., & Hilley, C. (2018). A Meta-Analysis of Parenting Practices and Child Psychosocial Outcomes in Trauma-Informed Parenting Interventions after Violence Exposure. *Prevention Science*, 19(7), 927–938. <https://doi.org/http://dx.doi.org/10.1007/s11121-018-0943-0>
- Loechner, J., Starman, K., Galuschka, K., Tamm, J., Schulte-Körne, G., Rubel, J., & Platt, B. (2018). Preventing depression in the offspring of parents with depression: A systematic review and meta-analysis of randomized controlled trials. *Clinical Psychology Review*, 60, 1–14. <https://doi.org/10.1016/j.cpr.2017.11.009>
- Maclean, M. J., Sims, S., O'Donnell, M., & Gilbert, R. (2016). Out-of-home Care versus In-home Care for Children Who Have Been Maltreated: A Systematic Review of Health and Wellbeing Outcomes. *Child Abuse Review*, 25(4), 251–272. <https://doi.org/10.1002/car.2437>
- Marcellus, L., MacKinnon, K., Gordon, C., & Shaw, L. (2021). Interventions and programs that support the health and development of infants with prenatal substance exposure in foster care: a scoping review. *JBI Evidence Synthesis*, 19(8), 1844–1886. <https://doi.org/10.11124/JBIES-20-00071>
- Marie-Mitchell, A., & Kostolansky, R. (2019). A Systematic Review of Trials to Improve Child Outcomes Associated With Adverse Childhood Experiences. *American Journal of Preventive Medicine*, 56(5), 756–764. <https://doi.org/10.1016/j.amepre.2018.11.030>

- Mitra, R., & Hodes, M. (2019). Prevention of psychological distress and promotion of resilience amongst unaccompanied refugee minors in resettlement countries. *Child: Care, Health and Development*, 45(2), 198–215. <https://doi.org/10.1111/cch.12640>
- Montgomery, P., Gardner, F., Bjornstad, G., & Ramchandani, P. (2009). *Systematic reviews of interventions following physical abuse: helping practitioners and expert witnesses improve the outcomes of child abuse*. Retrieved from <https://www.researchgate.net/publication/237416324>
- Morton, M. H., Kugley, S., Epstein, R., & Farrell, A. (2020). Interventions for youth homelessness: A systematic review of effectiveness studies. *Children and Youth Services Review*, 116, 1–13. <https://doi.org/10.1016/j.chilyouth.2020.105096>
- Newton, K., Taylor Buck, E., Weich, S., & Uttley, L. (2020). A review and analysis of the components of potentially effective perinatal mental health interventions for infant development and mother-infant relationship outcomes. *Development and Psychopathology*, 34(1), 37–54. <https://doi.org/10.1017/S0954579420001340>
- Niccols, A., Milligan, K., Smith, A., Sword, W., Thabane, L., & Henderson, J. (2012). Integrated programs for mothers with substance abuse issues and their children: a systematic review of studies reporting on child outcomes. *Child Abuse & Neglect*, 36(4), 308–322. <https://doi.org/10.1016/j.chiabu.2011.10.007>
- Nilsen, W., Johansen, S., Blaasvær, N., Hammerstrøm, K. T., & Berg, R. C. (2015). *Effect of Interventions Targeting Incarcerated Parents and Their Children* (Vol. 15–2015). Retrieved from https://www.ncbi.nlm.nih.gov/books/NBK390563/pdf/Bookshelf_NBK390563.pdf
- Noh, D. (2018). Psychological Interventions for Runaway and Homeless Youth. *Journal of Nursing Scholarship*, 50(5), 465–472. <https://doi.org/10.1111/jnu.12402>
- O’Higgins, A., Ott, E. M., & Shea, M. W. (2018). What is the Impact of Placement Type on Educational and Health Outcomes of Unaccompanied Refugee Minors? A Systematic Review of the Evidence. *Clinical Child and Family Psychology Review*, 21(3), 354–365. <https://doi.org/10.1007/s10567-018-0256-7>
- Oja, C., Edbom, T., Nager, A., Månsson, J., & Ekblad, S. (2020). Informing children of their parent’s illness: A systematic review of intervention programs with child outcomes in all health care settings globally from inception to 2019. *PLoS ONE*, 15(5), 1–24. <https://doi.org/10.1371/journal.pone.0233696>
- Phillips, S. D., Gleeson, J. P., & Waites-Garrett, M. (2009). Substance-Abusing Parents in the Criminal Justice System: Does Substance Abuse Treatment Improve Their Children’s Outcomes? *Journal of Offender Rehabilitation*, 48(2), 120–138. <https://doi.org/10.1080/10509670802640925>
- Piegenschke, K., Sihorsch, M., & Christiansen, H. (2019). Begleitete minderjährige Geflüchtete: Eine systematische Übersicht über psychologische Interventionen mit Familieneinbezug (Accompanied refugee minors: A systematic review of psychological interventions with family inclusion). *Kindheit Und Entwicklung: Zeitschrift Für Klinische Kinderpsychologie*, 28(3), 147–159. <https://doi.org/10.1026/0942-5403/a000285>
- Poli, C. F., Molgora, S., Marzotto, C., Facchin, F., & Cyr, F. (2017). Group Interventions for Children Having Separated Parents: A Systematic Narrative Review. *Journal of Divorce & Remarriage*, 58(8), 559–583. <https://doi.org/10.1080/10502556.2017.1345243>
- Poobalan, A. S., Aucott, L. S., Ross, L., Smith, W. C. S., Helms, P. J., & Williams, J. H. G. (2007). Effects of treating postnatal depression on mother-infant interaction and child development: Systematic review. *British Journal of Psychiatry*, 191, 378–386. <https://doi.org/10.1192/bjp.bp.106.032789>
- Rayce, S. B., Rasmussen, I. S., Skovgaard Væver, M., & Pontoppidan, M. (2020). Effects of parenting interventions for mothers with depressive symptoms and an infant: Systematic review and meta-analysis. *BJPsych Open*, 6(e9), 1–10. <https://doi.org/10.1192/bjo.2019.89>
- Reupert, A. E., Cuff, R., Drost, L., Foster, K., van Doesum, K. T. M., & van Santvoort, F. (2013). Intervention programs for children whose parents have a mental illness: a review. *Medical*

- Journal of Australia*, 199(3 Suppl), 18–22. <https://doi.org/10.5694/mja11.11145>
- Rizo, C. F., Macy, R. J., Ermentrout, D. M., & Johns, N. B. (2011). A review of family interventions for intimate partner violence with a child focus or child component. *Aggression and Violent Behavior*, 16(2), 144–166. <https://doi.org/10.1016/j.avb.2011.02.004>
- Roberts, L., Maxwell, N., Rees, P., Holland, S., & Forbes, N. (2016). Improving well-being and outcomes for looked after children in Wales: a context sensitive review of interventions. *Adoption and Fostering*, 40(4), 309–324. <https://doi.org/10.1177/0308575916675563>
- Ruff, S., McComb, J. L., Coker, C. J., & Sprenkle, D. H. (2010). Behavioral couples therapy for the treatment of substance abuse: a substantive and methodological review of O'Farrell, Fals-Stewart, and colleagues' program of research. *Family Process*, 49(4), 439–456. <https://doi.org/10.1111/j.1545-5300.2010.01333.x>
- SBU Assessments. (2017). *Interventions to improve foster children's mental and physical health: A systematic review and assessment of the economic, social and ethical aspects*. Swedish Agency for Health Technology Assessment and Assessment of Social Services. Retrieved from http://www.sbu.se/contentassets/890c0a078ca342ef8f3df817acb4f2/interventions_improve_foster_childrens_mental_physical_health_2017_smf.pdf
- Schoemaker, N. K., Wentholt, W. G. M., Goemans, A., Vermeer, H. J., Juffer, F., & Alink, L. R. A. (2020). A meta-analytic review of parenting interventions in foster care and adoption. *Development and Psychopathology*, 32(3), 1149–1172. <https://doi.org/10.1017/S0954579419000798>
- Schrader McMillan, A., Barlow, J., Stewart Brown, S., Carter, Y., Sidebotham, P., & Moli, P. (2008). *A systematic review of interventions for the secondary prevention and treatment of emotional abuse of children by primary carers*. Warwick Medical School, University of Warwick. Retrieved from <http://wrap.warwick.ac.uk/2906/>
- Siegenthaler, E., Munder, T., & Egger, M. (2012). Effect of preventive interventions in mentally ill parents on the mental health of the offspring: systematic review and meta-analysis. *Journal of the American Academy of Child & Adolescent Psychiatry*, 51(1), 8–17. <https://doi.org/10.1016/j.jaac.2011.10.018>
- Silverman, W. K., Ortiz, C. D., Viswesvaran, C., Burns, B. J., Kolko, D. J., Putnam, F. W., & Amaya-Jackson, L. (2008). Evidence-based psychosocial treatments for children and adolescents exposed to traumatic events. *Journal of Clinical Child and Adolescent Psychology*, 37(1), 156–183. <https://doi.org/10.1080/15374410701818293>
- Slesnick, N., Dashora, P., Letcher, A., Erdem, G., & Serovich, J. (2009). A Review of Services and Interventions for Runaway and Homeless Youth: Moving Forward. *Children & Youth Services Review*, 31(7), 732–742. <https://doi.org/10.1016/j.childyouth.2009.01.006>
- Solomon, D. T., Niec, L. N., & Schoonover, C. E. (2017). The Impact of Foster Parent Training on Parenting Skills and Child Disruptive Behavior: A Meta-Analysis. *Child Maltreatment*, 22(1), 3–13. <https://doi.org/10.1177/1077559516679514>
- Templer, K., Matthewson, M., Haines, J., & Cox, G. (2017). Recommendations for best practice in response to parental alienation: findings from a systematic review. *Journal of Family Therapy*, 39(1), 103–122. <https://doi.org/10.1111/1467-6427.12137>
- Thanhäuser, M., Lemmer, G., de Girolamo, G., & Christiansen, H. (2017). Do preventive interventions for children of mentally ill parents work? Results of a systematic review and meta-analysis. *Current Opinion in Psychiatry*, 30(4), 283–299. <https://doi.org/10.1097/YCO.0000000000000342>
- Troy, V., McPherson, K. E., Emslie, C., & Gilchrist, E. (2018). The Feasibility, Appropriateness, Meaningfulness, and Effectiveness of Parenting and Family Support Programs Delivered in the Criminal Justice System: A Systematic Review. *Journal of Child and Family Studies*, 27(6), 1732–1747. <https://doi.org/10.1007/s10826-018-1034-3>
- Turner, W., Macdonald, G., & Dennis, J. A. (2007). Behavioural and cognitive behavioural training interventions for assisting foster carers in the management of difficult behaviour (Review).

- Cochrane Database of Systematic Reviews*, (1), 1–50.
<https://doi.org/10.1002/14651858.CD003760.pub3>
- Uretsky, M. C., & Hoffman, J. A. (2017). Evidence for Group-Based Foster Parent Training Programs in Reducing Externalizing Child Behaviors: A Systematic Review and Meta-Analysis. *Journal of Public Child Welfare*, 11(4–5), 464–486. <https://doi.org/10.1080/15548732.2017.1326360>
- Van Andel, H. W. H., Grietens, H., Strijker, J., Van der Gaag, R. J., & Knorth, E. J. (2014). Searching for effective interventions for foster children under stress: a meta-analysis. *Child & Family Social Work*, 19(2), 149–155. <https://doi.org/10.1111/j.1365-2206.2012.00885.x>
- Waechter, R. L., & Wekerle, C. (2015). Promoting Resilience Among Maltreated Youth Using Meditation, Yoga, Tai Chi and Qigong: A Scoping Review of the Literature. *Child & Adolescent Social Work Journal*, 32, 17–31. <https://doi.org/10.1007/s10560-014-0356-2>
- Williamson, K., Landis, D., Shannon, H., Gupta, P., & Gillespie, L.-A. (2017). *The Impact of Protection Interventions on Unaccompanied and Separated Children in Humanitarian Crises*. Humanitarian Evidence Programme. Oxford: Oxfam GB. Retrieved from <https://oxfamlibrary.openrepository.com/bitstream/10546/620204/1/rr-protection-intervention-impact-children-030317-en.pdf>
- Wilson, B., & Barnett, L. M. (2020). Physical activity interventions to improve the health of children and adolescents in out of home care — A systematic review of the literature. *Children and Youth Services Review*, 110, 1–20. <https://doi.org/10.1016/j.childyouth.2020.104765>
- Winokur, M. A., Holtan, A., & Batchelder, K. E. (2014). Kinship Care for the Safety, Permanency, and Well-being of Children Removed from the Home for Maltreatment: A Systematic Review. *Campbell Systematic Reviews*, 10(1), 1–292. <https://doi.org/10.4073/csr.2014.2>
- Winokur, M. A., Holtan, A., & Batchelder, K. E. (2018). Systematic Review of Kinship Care Effects on Safety, Permanency, and Well-Being Outcomes. *Research on Social Work Practice*, 28(1), 19–32. <https://doi.org/10.1177/1049731515620843>
- Xu, Y., & Bright, C. L. (2018). Children’s mental health and its predictors in kinship and non-kinship foster care: A systematic review. *Children and Youth Services Review*, 89, 243–262. <https://doi.org/10.1016/j.childyouth.2018.05.001>
- Ziviani, J., Feeney, R., Cuskelly, M., Meredith, P., & Hunt, K. (2012). Effectiveness of support services for children and young people with challenging behaviours related to or secondary to disability, who are in out-of-home care: A systematic review. *Children and Youth Services Review*, 34(4), 758–770. <https://doi.org/10.1016/j.childyouth.2012.01.002>