
Dementia Implementation Plan Review: its role in dementia policy and future perspectives

COMMUNICATION | EDITORIAL | INVITED CONTRIBUTION | PERSPECTIVE | REPORT | REVIEW

Bogdan Kobierskij
Cambridge Judge Business School
University of Cambridge

ABSTRACT

This work reviews dementia policy in the UK using the Prime Minister’s Dementia Challenge 2020 Implementation Plan and the Phase 1 Review of the plan provided by the Department of Health and Social Care (DHSC). The proposed Implementation Plan is aimed at making the UK the best country in the world for dementia care and research. In order to achieve this goal, the plan concentrates on the four key aspects of the new dementia policy, which are risk reduction, health and care, awareness and social action, and research. This policy report is based on data provided by the DHSC and Alzheimer’s Research UK (ARUK). Here, the Implementation Plan and the Phase 1 Review are compared to illustrate the progress achieved so far, as well as to suggest recommendations. Whilst the commitments of the plan have been partially achieved, improvement is still required, including but not limited to improved risk awareness and patent protection policies.

SCIENCE \Rightarrow POLICY

The article illustrates several weak points in UK dementia policy which should be addressed to tackle the dementia problem in the country. Policymakers should devote more attention to the participation in clinical trials, the engagement of minority groups, risk factors and develop more accurate metrics. Suggested options include stronger patent protection, the greater role of Informed Consent, better inclusion, and others. The proposed measures are expected to improve the existing anti-dementia policy in the UK.

Keywords Dementia · The United Kingdom · Risk Factors · Implementation Plan · Phase 1 Review

Dementia Problem in the United Kingdom

The World Health Organisation (WHO) defines dementia as a progressive syndrome which causes deterioration in cognitive function [1]. It affects memory, thinking, orientation, comprehension, calculation, learning capacity, language, and

judgement. However, consciousness is not affected. “The impairment in cognitive function is commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behaviour, or motivation” [1]. According to Alzheimer’s Research UK (ARUK) Dementia Statistics Hub, 885,000 people in the UK live with dementia, of which 127,000 have mild dementia, 246,000 have moderate dementia and 511,000 have severe dementia [2].

However, due to poor public awareness, only 474,693 people were diagnosed with dementia by their GPs [3]. The current cost of dementia in the UK is £26 billion, and it is expected to more than double by 2040, reaching the sum of £55 billion [4]. As for the number of people with dementia, figure 1 shows that it will also grow rapidly and is expected to be more than 2 million people by 2050 [4].

One of the key factors contributing to dementia growth in the UK is increasing life expectancy, because age is the primary risk factor for dementia alongside other risk factors including diabetes and cardiovascular diseases. Dementia is now one of the main causes of death in the UK: in 2017, 13% of the total population of the UK died due to dementia, which prevailed over other causes of death like ischaemic heart and cerebrovascular diseases [4]. Figure 2 shows the increase in deaths caused by dementia from 2005 to 2017 [4].

Moreover, by 2040 deaths due to dementia are estimated to exceed those as a result of cancer in the UK [4]. According to a 2017 Ipsos MORI Health, Ageing and Support Survey, 52% of people thought that dementia was the biggest health problem facing older people [5].

Dementia Policy Implementation Plan: Findings from Phase 1 Review

The primary aim of the Implementation Plan, which was published on 6th March 2016, was to provide a useful framework to develop high quality, fully integrated dementia health and care services that are aligned with the commitments in the Prime Minister's Challenge on Dementia 2020. This Challenge aimed to make England, by 2020, the best country in the world for dementia care, support, research and awareness [6]. In 2019, the Government published the Phase 1 Review to assess the progress of the new policy. This was especially important because Brexit negotiations are likely to have an impact on the research industry; leaving the European Union could result in losing financial support for research, some European researchers, and participation in clinical

trials, although it is not possible to estimate such an impact yet [7].

The Plan includes four key aspects:

1. risk reduction
2. health and care delivery
3. awareness and social action
4. research

Risk Reduction

Dementia risk indicators were developed to provide local authorities with an understanding of dementia risk level in their local populations. The Medical Research Council, supported by the Wellcome Trust, invested £34 million in the UK Biobank to carry out a clinical study on 100,000 participants, which is expected to create the largest dataset in the world about dementia risk factors [6]. These actions are expected to delay the prevalence of dementia in the population as well as inform people at high risk how to reduce it. The plan does not include the list of particular risk factors which should be taken into account. Although, existing research provides sufficient evidence on risk factors such as cardiovascular diseases, obesity, smoking, lower level of education and diabetes, which could be included in the plan [8–11]. Despite the fact that some guidance on risk factors was provided to the public as a part of the “One You” NHS campaign, certain social groups including Black and Minority Ethnic (BAME) and non-English speakers are not included in the information programme [7].

Health and Care

The Department of Health and Social Care (DHSC) has published a declaration on post-diagnostic care and support [12]. This document introduces the collaboration of the Government, patients and non-governmental organisations like Alzheimer's Society, Dementia UK and others, which provides support for families and raises funds to help people living with dementia. GPs are now responsible for the development and realisation of personalised care plans for dementia patients. They are working in tight collaboration

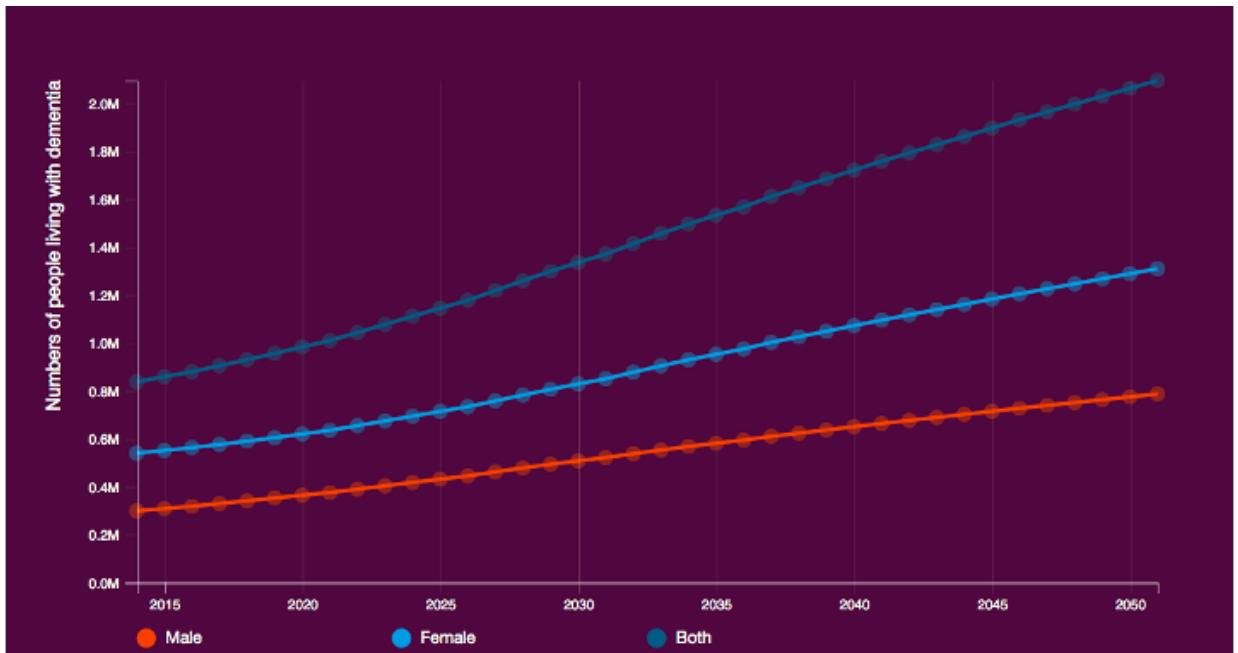


Figure 1: Number of people living with dementia, 2019 (Source: Alzheimer’s Research UK, 2021)



Figure 2: Deaths caused by dementia (Source: Alzheimer’s Research UK, 2021)

with memory assessment services and care institutions to better develop personalised care plans which provide patients, healthcare professionals and carers with a clear vision of their treatment. The Phase 1 Review concludes that health and care commitment has been partially met nationally, but the diagnosis rate across the country is inconsistent – current diagnosis metrics need improvement [7].

Awareness and Social Action

The Awareness and Social Action programme includes three main commitments. The first one is the creation of Dementia Friends, a volunteer network, responsible for raising awareness of the dementia problem in society. They run information sessions in their communities and provide care to local people diagnosed with dementia [13]. Although the number of Dementia Friends only reached 3 million out of its initial 4 million target, it was still concluded that the primary aim of raising social awareness was achieved by the Government [7]. Local and central governments also participate in the programme. The civil service Dementia Friends programme trained around 35,000 Dementia Friends [7]. Secondly, the plan promoted Dementia Friendly Communities (DFCs) run by ARUK, which contributed to inclusion and improving the quality of life for people with dementia by the creation of Memory Cafés, where patients with dementia can meet health professionals and members of local community, and by the use of social media platforms for information campaigns and news sharing. In 2019, 346 areas signed up to be DFCs – this is two times more than in 2016 [7]. A third programme mentioned in the plan is Dementia Friendly Businesses. By 2018, more than 11,000 organisations committed to be Dementia Friendly, which includes supporting staff affected by dementia as well as clients with dementia [7]. According to the Dementia Friendly Awards 2019, HSBC UK was recognised as the Dementia Friendly Organisation of the Year.

Overall, all these three commitments were estimated to have a positive influence [7]. However, the Phase 1 Review criticised the plan for excluding ethnic minorities and non-English speakers

from the awareness programme and recommended to engage these groups [7].

Research

The research commitments of the Implementation Plan include increased investment in dementia research and obtaining a greater number of participants in clinical trials for prospective dementia treatments. This is necessary for the creation of the Join Dementia Research database, a service which allows people to register their interest in participating in dementia research and be matched to suitable studies. The Government invests £60 million per year in dementia research; this is twice as much as it was investing before the Implementation Plan [6, 7]. In addition, the UK Dementia Research Institute acquired a total sum of £290 million from ARUK and other NGOs [7]. Also, ARUK is trying to encourage more academics to focus their research on dementia by delivering research funding and creating the Drug Discover Alliance. This is expected to attract specialists to the problem as well as getting patients to participate in clinical trials. Current treatment trials are expected to provide results by 2025. According to The Trajectory of Dementia in the UK report, if new treatment slows the progression of dementia by 25%, by 2050 there will be 6% fewer people who suffer from severe forms of dementia [14]. However, there are goals which have not been achieved yet – only 1% out of an expected 25% joined the Join Dementia Research database [6, 7].

The plan also includes the creation of the Dementia Discovery Fund (DDF) – a venture capital fund aimed at boosting dementia research; investors are leading pharmaceutical companies, NGOs and the Government, which altogether have committed more than \$100 million to the fund [6]. The Phase 1 Review does not include any information on the fund's performance.

Future Directions

According to the Phase 1 Review, the Implementation Plan has partially achieved its goals in some areas but still has space for improvement [7]. In particular, the plan ignores minority groups

such as ethnic minorities, non-English speakers, and people with mental and physical health challenges, who must be included in the risk reduction and awareness programmes [7]. Also, the plan does not specify the risk factors of dementia. Including such factors could contribute to a risk reduction programme by raising awareness of potential causes of dementia [8–11]. It is crucial that the scope of risk factors is not limited to only health issues like smoking or obesity. Other factors should also be taken into account. Existing analysis shows that education also plays a role dementia prevention [15]. According to the Phase 1 Review, the number of people participating in clinical trials is smaller than expected – only 1% of dementia patients instead of 25% [7]. Including information about clinical trials of prospective treatment into the awareness materials could help to improve the participation rate. Also, the informed consent document could be made in a way which emphasises the benefits of free dementia treatment for the subjects – this could possibly contribute to the research goal.

The Implementation Plan concentrates exclusively on developing treatment options, whereas it could also emphasise the improvement of the existing methods of treatment. In particular, it is crucial to devote attention to a combination treatment of donepezil and memantine, since this is considered to be the most effective patient prescription plan today [16]. The affordability of dementia treatment could be improved if the Government invested more in cheaper generic copies of memantine and donepezil - the patents on which have already expired, and formula is available - because a memantine and donepezil course is usually prescribed for long-term treatment. Affordable drugs could counterbalance the financial burden of carers [17]. Despite the fact that the plan sets the ambitious goal of “making the UK the best country for people with dementia”, it does not include any changes in the existing regulation [6]. The plan should propose the longer patent protection of prospective dementia drugs. Being the strongest stimulator for socially valuable research, longer and broader patents are likely to nudge pharmaceutical companies to switch from just financing the DDF to conducting R&D themselves to obtain the dementia drug market share [18, 19].

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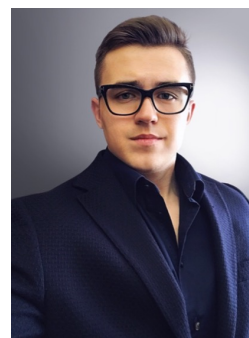
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About the Author

I am a student in in the MPhil in Technology Policy at the Cambridge Judge Business School. I have a background in law and clinical trials. My previous work experience includes risk analysis, legal consulting, and business development. I am interested in public-private partnerships and their impact on public policy. Corresponding address: bk434@jbs.cam.ac.uk.



Conflict of interest The Author declares no conflict of interest.