

House of Lords – Health and Care Bill (Clause 21) – 1st & 3rd March 2022

1. Background

Dementia is one of the leading causes of death in the UK with an estimated 900,000 people currently living with the condition.¹ Dementia is a progressive, long-term health condition with no disease-modifying treatment in the UK. Not only does this cause harm and heartbreak to millions of families, it is also completely unsustainable for our current health and social care system.

Alzheimer's Society and Alzheimer's Research UK are working together to support an amendment to the Health and Care Bill put forward by Lord McColl, which will improve the lives of people affected by dementia.

2. Amendment overview

Integrated Care Partnerships (ICPs) exist to integrate health and social care and are being placed on statutory footing under the Health and Care Bill. **As people affected by dementia and their care givers are the largest group of people who draw upon both health and social care**, they have the most to gain from linking the systems which contribute to the dementia pathway.

Lord McColl's amendment would require ICPs to consider the needs of those with dementia in preparing their integrated care strategies. It requires an ICP to plan how it would a) consistently meet or exceed the target dementia diagnosis rate of 66.7% and b) improve public participation in dementia research.

Both aims are crucial to improving the experiences of people living with dementia and to accelerating progress in dementia research. More broadly, incorporating plans for people with dementia into every ICPs' strategies would keep the needs of people affected by dementia at the top of the agenda.

3. Improving dementia diagnosis rates

Not everyone with dementia has currently received a diagnosis. A diagnosis allows people to plan for the future, participate in research and unlock vital extra support. It further enables clinicians to offer health and lifestyle advice and interventions to modify and reduce risk of disease progression. This is not only important for the individual, but also for reducing pressure on the NHS: up to 65% of emergency admissions for people living with dementia could be avoided if they had the right support.²

Since 2015, the UK had been consistently meeting the national target of 66.7% of people with dementia receiving a diagnosis.³ However, the pandemic has negatively affected dementia diagnosis rates, with **the national rate significantly declining from 67.6% in January 2020 to just 61.6% in January 2022.**⁴

As the national diagnosis rate has declined, the backlog of people waiting to receive a diagnosis has grown. We estimate that there are **an extra 35,000 people living in the dark about their dementia status than there would have been had the pandemic not happened.**⁵

Diagnosis rates won't improve without a proper strategy at a local level, with rates continuing to fall.⁶ Specific factors such as rurality and large ethnic minority populations also require different approaches. Local strategies will be key to improving the diagnosis rate.

If we are to position the UK as a world leader in dementia research, transforming the way we diagnose dementia is key, enabling us to identify patients to take part in trials at an earlier stage in their disease progression while also ensuring a clear diagnosis of dementia sub-type.

¹ Wittenberg, Raphael et al. Projections of older people with dementia and costs of dementia care in the United Kingdom, 2019-2040. 2019. Care Policy and Evaluation Centre, London School of Economics and Political Science. https://www.alzheimers.org.uk/sites/default/files/2019-11/cpec_report_november_2019.pdf.

² <https://www.alzheimers.org.uk/news/2021-05-17/emergency-admissions-dementia-care-failures-soaring-and-worse-come-warns-charity>

³ NHS Digital. Recorded Dementia Diagnoses. <https://digital.nhs.uk/data-and-information/publications/statistical/recorded-dementia-diagnoses>.

⁴ Ibid.

⁵ The gap between the number of people estimated to have dementia and those with a diagnosis has grown, meaning that in total 264,754 people with dementia don't have a diagnosis according to NHS digital.

⁶ NHS Digital. Recorded Dementia Diagnoses.

The lack of early and accurate diagnosis makes it challenging to find suitable candidates for clinical trials, ultimately slowing progress towards a potential disease-modifying treatment. **It is estimated that around 86% of people who put themselves forward for clinical research do so when their condition has worsened to the point that they are no longer suitable⁷.** There is evidence that dementia is more likely to be treatable when it is at an early stage, and drug development is currently focussed on delivering a treatment that could slow progression for patients with the earlier stages of Alzheimer's disease⁸.

4. Improving dementia research participation

The NHS has great potential for data sharing between research and clinical practice, and the focus on place-based leadership via Integrated Care Systems offers new opportunities to drive participation in clinical research. **However, whilst 69% of the public would be willing to take part in dementia research⁹, 81% stated they would not know how to volunteer.¹⁰**

Closer collaboration between Integrated Care Systems and researchers is the best way to make research participation usual around the country. The APPG on Dementia recently recommended that all newly diagnosed patients should receive a letter from the NHS within three months of their diagnosis providing information about how they can take part in dementia research, as clinicians often do not have the time, information, or incentive to personally invite people to contribute.¹¹

Further collaboration would also boost existing, underutilised infrastructure, including allowing the service Join Dementia Research (JDR) to be integrated with electronic patient records.¹² JDR is a service for which Alzheimer's Society and Alzheimer's Research UK are partners, which allows people to register their interest in participating in dementia research and be matched to suitable studies.¹³ As part of the 2020 Challenge on Dementia, the Government set out an ambition to have 25% of people living with dementia registered with JDR.¹⁴ **However, data from October 2021 indicates that just 1% of people diagnosed with dementia in England are currently registered with the service.¹⁵**

Not only will the integration of research into ICPs turbocharge research participation, it will also ensure that innovation can be easily applied from research into clinical practice. It's crucial that people living with dementia in the UK are given access to new innovative treatments and the best models of care as soon as possible.

5. Conclusion

Lord McColl's amendment introduces a requirement for ICPs to consider the needs of those with dementia in preparing their integrated care strategies, with specific focus on improving dementia diagnosis and research participation. For this to be achieved, the Department of Health and Social Care's Dementia Strategy, due to be published later this year, must deliver an ambitious plan to improve and transform dementia diagnosis, whilst placing research at the heart of the strategy.

For more information, contact Dan Simpson at dan.simpson@alzheimers.org.uk or Chelsea Wade at chelsea.wade@alzheimersresearchuk.org.

⁷ Alzheimer's Research UK, Translating science into breakthroughs, 2021, [FUTURE-OF-CLINICAL-TRIALS-FINAL.pdf \(alzheimersresearchuk.org\)](#)

⁸ Alzheimer's Research UK, The Right to Know, Accurate and Earlier Diagnosis of Dementia, 2021, [ARUK-The-Right-to-Know-Accurate-and-Earlier-Diagnosis-of-Dementia_25May21.pdf \(alzheimersresearchuk.org\)](#)

⁹ Alzheimer's Research UK, Dementia Attitudes Monitor 2021, [Public attitudes towards dementia \(dementiastatistics.org\)](#)

¹⁰ National Institute for Health and Care Excellence. Dementia Quality Standards Briefing. 2018. <https://www.nice.org.uk/guidance/gs184/documents/briefing-paper>.

¹¹ APPG on Dementia. Fuelling the Moonshot. 2021. https://www.alzheimers.org.uk/sites/default/files/2021-09/Fuelling_Moonshot_APPG.pdf.

¹² Ibid.

¹³ National Institute for Health Research. About Join Dementia Research. 2021. <https://www.joindementiaresearch.nihr.ac.uk/content/about>.

¹⁴ UK Government. Prime Minister's Challenge on Dementia 2020. 21 February 2015. <https://www.gov.uk/government/publications/prime-ministers-challenge-on-dementia-2020/prime-ministers-challenge-on-dementia-2020>.

¹⁵ National Institute for Health Research. Join Dementia Research Volunteer Registration Data. 4 October 2021. <https://nhs.joindementiaresearch.nihr.ac.uk/data-and-statistics/>.