



## The impact of COVID-19 on dementia research and people living with dementia

### Written evidence for the APPG on Coronavirus

No group has been hit harder by the COVID-19 pandemic than those affected by dementia. A sharp spike in deaths of people with dementia, both with COVID-19 and without, has been coupled with a devastating increase in social isolation. There has been significant disruption to research seeking to find much-needed treatments to improve the lives of those living with dementia. And uncertainty continues to surround the neurological impacts of COVID-19 itself, particularly in the long term.

The UK Dementia Research Institute (UK DRI) is the UK's national dementia research institute, founded in 2017 to provide the UK with a world-class institute to lead research efforts against dementia. Our initial investment of £290m represents the largest single investment the UK has ever made into dementia research. Our ambition to make breakthroughs in dementia research that will transform lives is undimmed despite the current crisis, though there have been significant impacts on our work.

This evidence, prepared by the UK DRI to inform the APPG's ongoing inquiry into the impacts of COVID-19, details how the pandemic has affected dementia research and those affected by dementia.

### People living with dementia

Dementia is the leading cause of death in the UK, accounting for 12.7% of all deaths registered<sup>i</sup>. 850,000 people in the UK are living with dementia, due to rise to 1.6 million by 2040<sup>ii</sup>. It has a devastating impact on individuals, their families, and more widely on the NHS, the economy and our society. The total economic cost to the UK of dementia stands at £34.7bn per year, due to more than double to £94bn by 2040<sup>iii</sup>. The largest proportion of these costs is social care, paid by both families and by the state. No other disease costs as much.

Against this backdrop, the impact of COVID-19 has been enormous:

1. Between March and June 2020, 13,840 deaths of people with dementia involving COVID-19 were recorded in England and Wales, making dementia the most common pre-existing condition in recorded deaths<sup>iv</sup>.
2. Some research has suggested a biological link between severe COVID-19 symptoms and 'risk genes' for Alzheimer's disease<sup>v</sup> – the leading cause of dementia. The disproportionate impact of the pandemic on care homes is evidently affecting people with dementia: around 70% of care home residents have dementia<sup>vi</sup>.
3. A team of researchers from the UK DRI undertook a rapid study of the impacts of the COVID-19 outbreak on care homes. They found high rates of infection and mortality, with high rates of asymptomatic disease or atypical symptoms – in 43% and 18% of those testing positive respectively – making detection and containment more challenging<sup>vii</sup>.



4. The pandemic has also been associated with a sharp spike in excess deaths of people with dementia, in addition to those resulting from COVID-19. Between January and July 2020, 5,049 such deaths were recorded, with excess deaths nearly double the five-year average during the peak weeks of the pandemic<sup>viii</sup>. While these figures have since fallen, there has also been a sharp rise in excess deaths of people with dementia in private homes – 79% above the five-year average between 14 March and 11 September 2020<sup>ix</sup>. The exact causes of this increase have not yet been identified, but it is likely in part due to delays in accessing key health and care services.
5. Diagnosis of dementia has fallen during the pandemic, likely in part due to reduced access to healthcare services. The NHS assesses dementia diagnosis rates by comparing the number of people estimated to have dementia against the number of those, aged 65 or over, with a firm diagnosis. In February 2020 67.6% of those aged 65 or over estimated to have dementia had a diagnosis, but this had fallen to 63% by September 2020 – below the national target of 66.7%<sup>x</sup>. These are people missing out on essential care and treatment, and are living with the uncertainty of no firm diagnosis.
6. There is a great deal of uncertainty about the long-term neurological impacts of COVID-19, both on patients both with and without dementia. Research supported by the UK DRI has found neurological complications of COVID-19 can include brain inflammation, delirium and nerve damage<sup>xi</sup>, while other studies have indicated at least short-term cognitive deficits in those who have recovered from COVID-19<sup>xii</sup>. More research into the long-term effects of the virus on the brain is urgently needed.
7. Compounding the impact of the virus and the knock-on effects on health and care provision, has been an increase in social isolation with families or loved ones unable to visit care settings. Such isolation can be particularly distressing for people with dementia. A report by Alzheimer’s Society, a founding funder of the UK DRI, found that 53% of people with dementia living alone felt more lonely during lockdown. Isolation and loneliness are known to contribute to a quicker onset of symptoms. Indeed, the survey also found impacts on mental wellbeing and symptoms: 45% of those surveyed said lockdown had a negative impact on their mental health, while 82% reported an increase in dementia symptoms<sup>xiii</sup>.

## Dementia research

There are currently no viable treatments that can slow, stop or prevent dementia or the diseases which cause it, making research efforts all the more vital. The UK Government has launched a series of positive initiatives on dementia research. The Prime Minister’s challenge on dementia 2020 launched the UK DRI with the aim of making the UK the best place in the world for dementia research. In its 2019 election manifesto, the current Government pledged to double dementia research funding to over £160m annually – though that pledge has yet to be delivered.

The pandemic has impacted this research in numerous ways. Dementia research, already underfunded in comparison to the vast economic cost of the disease, can ill afford additional disruption. However, without targeted Government support it is likely that research will see significant setbacks, hindering efforts to find game-changing treatments and therapeutics for those living with dementia:



8. Many labs, including those at the UK DRI, were shutdown or saw research suspended during the pandemic. There is, of course, significant value in non-lab-based research efforts, and many on-screen activities such as data analysis, literature reviews or seminars and training have continued. Ultimately, however, inability to access labs has negatively affected many ongoing projects. A survey of dementia researchers by Alzheimer's Research UK, a founding funder of the UK DRI, found that 95% of researchers had seen projects delayed, while only 15% of research group leaders had resumed activity at their labs at more than 50% capacity by mid-September 2020<sup>xiv</sup>.
9. This disruption is felt by all, but particularly keenly by early career researchers, many of whom are on fixed-term contracts. The loss of 6 or more months of research has significant impacts not only on their immediate projects, but on the career prospects of those researchers. Surveys by both the British Neurological Association (BNA) and Alzheimer's Research UK found up to a third of dementia researchers are considering leaving the field<sup>xv</sup>.
10. The inability to access labs and the need to suspend projects has additional impacts on research tools and resources, such as mice or cell cultures – both of which are essential to pre-clinical dementia research. If labs are shut these resources may need to be destroyed. These resources are expensive to maintain and, if lost, can take many months to redevelop. In the case of mice, it can take up to a year for colonies of aged animals to be reinstated – meaning disruption now has implications long into the future.
11. The economic implications of COVID-19 are far-reaching and only beginning to be understood, but the charity sector is already feeling the impact. Medical research charities funded half of all publicly funded UK medical research in 2019, representing a total investment of £1.9bn in UK R&D<sup>xvi</sup>. The UK DRI is a joint investment from two such charities, Alzheimer's Society and Alzheimer's Research UK (along with the Medical Research Council) and has already seen its budget cut.

These fundraising medical research charities, an essential part of the UK's research environment, have been hit hard by COVID-19. Members of the Association of Medical Research Charities (AMRC) are bracing themselves for an average decrease of 41% in research spend over 2020/21, with uncertainty as to when spend may return to previous levels. Without Government intervention, the UK's uniquely valuable charitable medical research sector may be permanently damaged.

For dementia research, and institutes like the UK DRI, this uncertainty makes long-term planning far more difficult. Recruitment of post-doctoral researchers on 3 or 4 year contracts, for example, may be delayed as financial planning becomes increasingly difficult. This will have long-lasting negative impacts on research for years to come. Government support for medical research charities, as called for by the AMRC<sup>xvii</sup> can reduce this uncertainty and minimise the long-term impact on research progress.

12. Charitable research funding is not the only funding source impacted by the pandemic. The broader economic impact is likely to affect both public and private investment. The BNA survey found that 80% of neuroscience researchers are concerned that their research will be negatively impacted by insufficient funding<sup>xix</sup>. Likewise, 72% of the researchers surveyed by Alzheimer's Research UK said they had seen future funding opportunities decrease<sup>xx</sup>. This is a challenge for all medical research but would be felt acutely by a dementia research sector which has been historically underfunded and



finds itself on the cusp of losing a once-in-a-generation opportunity to focus research efforts.

13. As discussed above, COVID-19 brings with it a number of unanswered questions about the long-term impact of the virus on the brain. These are impacts that the UK DRI could and should be spearheading research into. However, at a time of increased disruption and decreased resource, it is difficult to see how the dementia research community can open this vital new horizon of research without additional Government support.
14. The pandemic has thrown into sharp relief the immediate value and urgency of the UK DRI's work. One example is the work of our Care Research and Technology Centre at Imperial College London, which brings together multi-disciplinary teams to create new technologies that enable people with dementia to live independently for longer in the home. The team has adapted its efforts to tackle the isolation felt by many people with dementia during the lockdown, building virtual 'community centres' to maintain vital contact and routine for those who need them<sup>xxi</sup>.
15. Despite the challenge posed by COVID-19, the prospects for making a positive impact on dementia have never been better. Initiatives by Government, charities and others have raised awareness of the impact of dementia on individuals and society, but have also mapped a route to a more optimistic future. Ground-breaking research and emerging technologies are rapidly expanding our understanding of the disease and pointing to potential treatments and preventative tools – giving much-needed hope to those affected by dementia. The future of dementia research should be bright, with the UK playing a leading role globally, but only if resources are committed now to safeguard the sector from the shock of COVID-19.

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<sup>i</sup>Office for National Statistics, *Leading causes of death, UK: 2001 to 2018*, (2020). Accessed 27 October 2020 at <https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/causesofdeath/datasets/leadingcausesofdeathuk>

<sup>ii</sup> Care Policy and Evaluation Centre, *Projections of older people with dementia and costs of dementia care in the United Kingdom, 2019–2040*, (2019). Accessed 27 October 2020 at [https://www.alzheimers.org.uk/sites/default/files/2019-11/cpec\\_report\\_november\\_2019.pdf](https://www.alzheimers.org.uk/sites/default/files/2019-11/cpec_report_november_2019.pdf)

<sup>iii</sup> *ibid*

<sup>iv</sup> Alzheimer's Society, *Worst Hit*, (2020). Accessed 27 October 2020 at <https://www.alzheimers.org.uk/sites/default/files/2020-09/Worst-hit-Dementia-during-coronavirus-report.pdf>

<sup>v</sup> Alzheimer's Research UK, *Alzheimer's Risk gene link to Covid-19 risk*, (2020). Accessed 27 October at <https://www.alzheimersresearchuk.org/alzheimers-risk-gene-link-to-covid-19-risk/>

<sup>vi</sup> Alzheimer's Society, *Dementia UK: Update*, (2014). Accessed 27 October 2020 at

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<sup>vii</sup> Graham et al, *SARS-CoV-2 infection, clinical features and outcome of COVID-19 in United Kingdom nursing homes*, (2020). Accessed 27 October 2020 at

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<sup>viii</sup> Alzheimer's Society, *Worst Hit*, (2020).

<sup>ix</sup>Office for National Statistics, *Deaths in private homes, England and Wales (provisional): deaths registered from 28 December 2019 to 11 September 2020*, (2020). Accessed 27 October 2020 at

<https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/articles/deathsinprivatehomesenglandandwalesprovisional/deathsregisteredfrom28december2019to11september2020>

<sup>x</sup> NHS Digital, *Recorded Dementia Diagnoses September 2020*, (2020). Accessed 27 October 2020 at <https://digital.nhs.uk/data-and-information/publications/statistical/recorded-dementia-diagnoses/september-2020>



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- <sup>xiii</sup> Alzheimer's Society, *Worst Hit*, (2020).
- <sup>xiv</sup> Alzheimer's Research UK, *One in three dementia scientists consider leaving research due to COVID-19*, (2020). Accessed 27 October at <https://www.alzheimersresearchuk.org/one-in-three-dementia-scientists-consider-leaving-research-covid-19/>
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- <sup>xvii</sup> Association of Medical Research Charities, *Life Sciences-Charity Partnership Fund*, (2020). Accessed 27 October 2020 at <https://www.amrc.org.uk/Handlers/Download.ashx?IDMF=1cf57b61-5794-46ff-b3a6-0814bc6e9127>
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