



*Making dementia a priority:
changing perceptions, practice and policy.*

Alzheimer Europe position on supporting dementia research in unprecedented circumstances

28 July 2020

1. Background

Alzheimer Europe and the undersigned organisations have come together to address the serious challenges facing the dementia research community which has been severely impacted by the COVID-19 pandemic.

The COVID-19 pandemic has caused disruption to all aspects of life across the world, as measures aimed at slowing the spread of the virus (physical and social distancing, lockdown, closing of places of work etc.) have interrupted normal ways of working. This is also true for researchers working in laboratory and clinical settings, where a multitude of overlapping issues (furloughing or redeployment of staff, closure of services etc.) have resulted in research being put on hold.

Additional issues around uncertainty over funding, the cancellation of research calls, as well as a shift in focus from funding bodies towards COVID-19, have left researchers in the field of dementia uncertain as to their futures.

The position statement highlights three overarching themes:

- The need for greater support and flexibility for existing dementia research projects
- The impact on dementia research funding streams as a result of COVID-19
- The need to prioritise dementia in post-pandemic future research.

Each section outlines the key challenges in the field of dementia research, concluding with recommendations as to how these challenges may best be addressed.

2. The effect on existing dementia research projects

Delays and interruptions to dementia research projects

As outlined above, the situation for a number of research projects has been particularly challenging as a result of the lockdown measures in a lot of countries which made it impossible for study participants to come for medical visits and significantly impacted recruitment of new research participants and follow up visits of enrolled research participants. In some instances, research premises were closed and research staff were furloughed.

As a response to these disruptions, a number of public research funders, including the European Union's Horizon2020 programme and the Innovative Medicines Initiative, as well as private research funders (e.g. national Alzheimer organisations) have shown great flexibility by allowing no-cost extensions of funded projects beyond the initially agreed project time scales. Similar flexibility was shown with regard to deadlines for project deliverables and for accepting costs related to meeting and travel cancellations and other costs directly caused by the COVID-19 pandemic. In some cases, funders allowed researchers to pivot their research towards COVID-19, although this will change the outcomes produced by projects and reduce the research efforts dedicated to dementia.

Whilst these measures are welcome, they still pose fundamental challenges, especially for dementia research projects, particularly those involving clinical research studies. These projects have faced interruptions at critical stages, including during participant recruitment and follow-up visits, with participants in dementia research often considered as high-risk categories. Moreover, as biobanks are operating at higher security levels, the processing and analysis of biosamples from dementia research participants has been interrupted.

Many researchers have already identified the need for considerable changes in the way research is both designed and delivered, as a result of the measures outlined above, developing

the opportunities for collaboration and improved scale and speed of research¹. Among the developments which have emerged, virtual participation and data collection are emerging as possible ways forward, however, there is recognition that this requires new ways of working and support for participants, especially people with dementia.

Funding implications for existing projects

The delays outlined above inevitably come with financial implications for projects, the research institutions involved and for researchers themselves (particularly those at an early stage of their careers).

For some research institutions, staff costs and overheads have stayed unchanged, but due to the pausing of research projects, these costs can no longer be funded through research projects and need to be covered by reserves or other funding sources. Some research institutions were able to furlough staff, where staff costs were covered by national emergency programmes, whereas other institutions may have had to make staff redundant through lack of funding. In these cases, the offer of “no-cost” extensions from research funders, whilst welcome, does not fully resolve the challenges facing research organisations and researchers themselves.

The effects on early-career researchers

The delays and associated cost implications have had a disproportionate impact on early-career researchers (ECRs), particularly those with caring responsibilities, or from disadvantaged or minority backgrounds. Graduate students have experienced the cessation of studies (or the moving of these studies online), while postdoctoral researchers have been furloughed or redirected to non-research activities. Many academic institutions have frozen their hiring, promotion and tenure rounds, whilst fellowship and grant application schemes have been cancelled. Furthermore, networking and professional development events, crucial to the career progression of ECRs, have been halted.

As a result of these circumstances, ECRs may have to shift their expertise to other areas, in line with available funding, or leave dementia research entirely.

Recommendations/call to action

Taking into consideration the above points, the signatories of this position statement call for:

- Research funders to show the maximum possible flexibility for funding recipients, to ensure resources can be allocated as required to allow for the completion of projects
- Research funders to work with recipients to ensure that existing data, findings and outputs from projects are collated
- Research organisations to offer flexibility and accommodation to researchers (especially early-career researchers), taking steps to provide opportunities and further development to ensure their continued career progression
- The EU and national governments, through economic responses to COVID-19 (e.g. the EU Recovery Instrument), to support research institutions and researchers to ensure they do not lose out financially.

¹ Richardson, S.J., Carroll, C.B., Close, J., Gordon, A.L., O'Brien, J., Quinn, T.J., Rochester, L., Sayer, A.A., Shenkin, S.D., van der Velde, N. and Woo, J., 2020. Research with older people in a world with COVID-19: identification of current and future priorities, challenges and opportunities. *Age and Ageing*.

3. The effect on dementia funding streams as a result of COVID-19

Loss of funding streams in 2020 for new research

As a result of the pandemic, the challenges for funders of dementia research have also come to the fore, with two key issues creating significant difficulties for the future of dementia research.

The first challenge relates to the approach of national, European and international funding bodies, including the EU/IMI, which have shifted their research focus towards COVID-19. Whilst this is understandable, it is important to note that the disparity in funding for dementia has been a long-standing challenge for researchers in the field. If new funding streams primarily focus on COVID-19, and some existing research projects also pivot towards the research on the virus, this disparity will increase. This will inevitably limit the ability of researchers to make progress in understanding dementia, as well as delaying efforts to develop high-quality care and treatment.

The second challenge relates to another category of research funders, namely those which rely on charitable donations and fundraised income to support dementia research. These organisations have experienced significant shortfalls in their income as a result of the COVID-19 pandemic, with many not in a position to continue offering similar levels of funding to previous years. In response to the uncertainty created by the COVID-19 pandemic, a number of funders have suspended their forthcoming funding rounds, or delayed funding decisions on recently-submitted applications.

Recommendations/call to action

Taking into consideration the above points, the signatories of this position statement call for:

- National research funders to resume, as early as is practicable, calls for dementia research
- The EU and national governments, through economic responses to COVID-19 (e.g. the EU Recovery Instrument), to ensure that research funding is not significantly diminished as a result of the pandemic.

4. Dementia research in a post-pandemic context

Comparatively lower funding for dementia research

Research into dementia and Alzheimer's disease has, proportionally, lagged behind that of other non-communicable diseases and chronic disease areas.

In 2013, the then-G8 issued a Communiqué² committing those countries to “set an ambition to identify a cure, or a disease-modifying therapy, for dementia by 2025” and “significantly increase the amount spent on dementia research”.

However, an analysis published in the *Lancet* in 2019³ examined the level of funding for dementia research in G7 countries, noting whilst there had been an overall increase in funding, this was as a result of increases from the UK and USA, with declines in other countries recorded. As an example of the comparatively lower levels of funding, the analysis also

² G8, 2013, G8 Dementia Summit Communiqué. Available at: <https://www.gov.uk/government/publications/g8-dementia-summit-agreements/g8-dementia-summit-communication>

³ Pickett, J. and Brayne, C., 2019. The scale and profile of global dementia research funding. *Lancet*, 394(10212), p.1888

identified that within the UK and USA, cancer research receives 4.5 times the level of funding of dementia research.

Re-prioritising and reimagining dementia research in a post-pandemic landscape

As we emerge from the COVID-19 pandemic, it is imperative that dementia research is re-prioritised. Whilst the focus on COVID-19 will likely continue until a vaccine is found, it must not be at the expense of other research areas. To do so would place fields such as dementia research under further pressure and risk their future viability and sustainability.

Programmes such as Horizon 2020 and the Joint Programme on Neurodegenerative Diseases (JPND) have provided invaluable funding for dementia research projects in recent years (including those funded through both IMI joint undertakings). There have been significant developments in recent years which have improved our understanding of the condition, as well as our ability to detect and diagnose it. However, there is still no disease-modifying treatment and no cure for dementia.

With ageing demographics in Europe set to result in the number of people living with dementia doubling by 2050⁴, the need for fairer research funding for dementia is evident.

Furthermore, many researchers have already identified the need for considerable changes in the way research is both designed and delivered, as a result of the measures outlined above, developing the opportunities for collaboration and improved scale and speed of research⁵. Among the developments which have emerged, virtual participation and data collection are emerging as possible ways forward, however, there is recognition that this requires new ways of working and support for participants, especially people with dementia. These shifts in approaches to dementia research will also raise new ethical challenges, which will require greater consideration.

A greater focus on care research

In addition to the concerns outlined about the funding for dementia research, it is also evident that there is an imbalance in the focus of research. The analysis from Pickett and Brayne (2019)², suggests that across the G7, an average of only 5% of government-funded dementia research is allocated for care research.

In addition, there is a need to understand how people with dementia and their carers have been impacted by COVID-19 and the lockdown measures put in place, which have resulted in many care and support services being withdrawn or restricted. In particular, further research is needed into the effect of COVID-19 restrictions on the psycho-social wellbeing of people with dementia and their carers, and on the best measures to counteract the detrimental effects of physical and social isolation on this group, such as technological or digital solutions and/or greater integration of professional and informal care networks. This would help guide governments and supranational bodies on how future measures can best be implemented.

Recommendations/call to action

Taking into consideration the above points, the signatories of this position statement call for:

⁴ Alzheimer Europe, 2019. *Dementia in Europe Yearbook 2019: Estimating the prevalence of dementia in Europe*. Available at:

⁵ Richardson, S.J., Carroll, C.B., Close, J., Gordon, A.L., O'Brien, J., Quinn, T.J., Rochester, L., Sayer, A.A., Shenkin, S.D., van der Velde, N. and Woo, J., 2020. Research with older people in a world with COVID-19: identification of current and future priorities, challenges and opportunities. *Age and Ageing*.

- National research funders and governments to provide increased funding and resources for dementia research, in line with other conditions (e.g. other non-communicable diseases) and reflecting the aims of the 2013 G8 Communiqué⁶
- National research funders, institutions and researchers should look explore the possibilities of adopting new ways of working, such as online and virtual platforms, where suitable, to allow research to continue even where physical distancing restrictions may continue, including the ethics of these new approaches
- The EU to include a dedicated strand of work dedicated to dementia research within the Horizon Europe research programme (2021-2027)
- National research funders should adopt an approach focused on prevention, care and cure, spanning the whole range of dementia research basic to care research
- Governments and research funders to give specific attention to the psycho-social aspects of dementia when assessing and considering the vulnerability of persons with dementia and their carers, including in relation to the impact of COVID-19.

⁶ G8, 2013, G8 Dementia Summit Communiqué. Available at: <https://www.gov.uk/government/publications/g8-dementia-summit-agreements/g8-dementia-summit-communicue>