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RECORD: Researching the Effects of Covid On Research in Dementia

Research Report

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Executive summary

During the Covid-19 pandemic, existing practical, ethical and social issues in dementia research have re-emerged with more complexity, compounded by additional challenges for researchers. This study sought to address this, provide space for discussion, and identify urgent issues and questions for the future of clinical research in dementia. Three focus group discussions were carried out online, comprising researchers from different clinical research sites working on similar aspects of dementia research (on-site, off-site, and investigator roles). Findings emerged under four main themes:

- **Impact of Covid on clinical research**: The de-prioritisation of dementia and precarious position of universities puts non-Covid related research under existential threat. A key question was how to effectively and ethically support and secure a process of re-prioritisation?
- **Impact on patients and participants - inclusion and access to dementia research:** Reducing the diversity of studies meant reducing diversity amongst participants. There have been direct (age-related) and indirect barriers to participation due to Covid. Indirect exclusions relate to other health burdens plus limited access to clinical research, care, and technologies. The pandemic is predicted to make dementia research less diverse.
- **Practical and ethical challenges to conducting dementia research:** The complex relationship between age, Covid risk, and dementia risk presented difficult practical and ethical problems to researchers. Risk-averse decisions to protect vulnerable participants and patients from Covid can exacerbate or "re-exclude" already underrepresented groups in clinical research.
- **The role of remote testing and digital biomarkers, during and post-pandemic:** There has been an increased need for remote technologies during lockdowns. However, there were split opinions between on-site and off-site groups about which model of phenotyping or assessment best enables prevention: digital phenotyping ('empowering' for the individual) or deep phenotyping (emphasising brain disease as treatable and preventable)?

Overall, participants were keen to harness new forms of data and technology to address two key issues that have been made more visible and amplified by the Covid-19 crisis: the importance of early prevention and access to care and research. However, the future of *how* technologies will and should be used in their broader social and scientific context remained uncertain and open for debate.

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Acknowledgements:

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Introduction

Prior to the Covid-19 pandemic, the focus of dementia research in recent years has been to understand longitudinal relationship between cognitive and biological change, to track the natural history of disease, and to generate a set of biological markers of the disease to enable clinical trials to test preventative treatments, rather than curative ones[1]. These aims have not changed since the pandemic, but there have been significant challenges to carrying out such research due to the effects of national lockdowns and prioritisation of Covid-related clinical research.[2]

Crucially, these dementia prevention studies *already* present unique social and ethical challenges, including those related to the return of results and the communication of risk states, recruitment approaches and study burden.[3–10] All this has particular significance for older adults, relating to their age and vulnerability to developing dementia symptoms as well as co-morbidities (ibid.). As studies resume after a year of restrictions and lockdowns, these issues have re-emerged with more complexity, and have been compounded by additional challenges for researchers.

Efforts have been made to track the effects of Covid-19 on investigators and participants in clinical research[11]. In the dementia and Alzheimer's disease field specifically, the benefits of continuing studies has had to be constantly weighed against the possibility of exposing older adults to the Coronavirus[12]. Concerns about the ethics of prioritising of certain resources and areas of clinical research/medicine at times of crisis have been raised; in particular, the possibility of excluding (or "re-excluding" as it emerged in this study) older people who are also clinically vulnerable. [2,13]

Despite this, clinical researchers have had little chance to step back and reflect upon their experiences in relation to broader implications of Covid-19 for dementia research and future challenges or problems that may emerge. Neither have there been many opportunities for researchers to share (potentially differing) perspectives on how dementia research might be done differently in the future; for example, the opportunities and/or pitfalls of using new technologies for cognitive assessments and (digital) phenotyping of Alzheimer's and dementia in a post-pandemic world[14,15]. This study sought to address this need and provide space for discussion, as well as identification of the key issues and urgent questions for the future of clinical research in dementia.

Methods

RECORD is a qualitative focus group study, developed in collaboration with the Oxford team of the MRC Dementias Platform UK Deep and Frequent Phenotyping (DFP) Study, which is a multi-centred UK-wide cohort study.

Three focus groups were carried out online, comprising researchers from *different sites* working on *similar aspects* of dementia research:

1. On-site clinical researchers (research coordinators and assistants)
2. Off-site researchers using digital and remote methods
3. Investigators leading clinical research at key sites

Recruitment was carried out via the DFP and its clinical and research networks using a snowball sampling technique. 10 participants were recruited from across sites and roles (4 participants in the first group and 3 participants in groups 2 and 3). They included clinical researchers from Oxford, Exeter, London, Edinburgh, Manchester, and Newcastle, as well as an industry partner and an academic involved in the broader dementia research network in the UK.

Each discussion took between 1.5 and 2 hours, depending on the size of the group, and the online sessions were video and audio recorded. Discussions were transcribed and analysed using thematic analysis using NVivo software.

Ethical approval for the study was granted by the University of Cambridge.

Findings

Impact of Covid on clinical research

Covid as an accelerator and amplifier

A key theme was of Covid as an accelerating and amplifying force for trends that were already emerging within and beyond dementia research. Whilst the majority of these shifts were concerning or negative, one largely positive shift thought to be accelerated by Covid, was towards the importance of primary prevention and "understanding brain health in mid-life" (Investigator, Clinical Research). The main acceleration discussed amongst all groups, however, was the process of digitisation across healthcare and academia:

> I feel like with Covid the forced move to online assessment has shown us what we could've been doing all along **(Digital health researcher, off-site)**

As we discuss in the final section of this report, there were numerous concerns about (potential) new issues emerging from this move to the digital sphere. Nevertheless, this process featured heavily in participants' discussions of the future of dementia research. Another connected theme, which focussed on the negative impact of the pandemic on inequalities that were already causing huge challenges to health and healthcare. This point is also developed in more detail below, in relation to the 're-exclusion' of already vulnerable or excluded groups (in particular, older people)

> Covid has, again, acted as a massive amplifier of huge socioeconomic issues and healthcare-related issues. **(Investigator, Clinical Research)**

Impact on academia

There were serious concerns amongst all groups and participants about the impact of Covid on universities and academia, with a particular focus on the experience and future possibilities for early career researchers. This places an existential threat to the work of dementia researchers, particularly in the UK, where much of their funding comes from charities who are "tightening their belts". In

addition, the move towards making "all knowledge virtual" (as this off-site participant went on to describe) meant that research was likely to slow down because of increased workloads, creating a temporary "dead zone of research" in the period immediately following the pandemic.

The ongoing and predicted impact on early career researchers (ECRs) was particularly pronounced with reports of "dire stats on how many people are leaving the field" (On site researcher group) and predictions that "ECRs from our space are going to disappear" (Investigators' group). In the short term, concerns centred around the lack of experience ECRs have been able to gain (especially as two research assistants had started their roles just as lockdown began). The ECRs in the on-site group described their situation working from home with limited access to progression as "being in limbo":

> I still feel as though I don't know what the future is going to look like for my job and for my role **(Research Assistant, On-site)**

Finally, there was little agreement on where focus should be for creating a more secure future, with some participants keen to collaborate with diverse partners, including industry, whilst others were mistrustful of such partnerships and advocated for moving research into the NHS.

Specific impact on dementia research: De-prioritisation

When it came to the effects of Covid specifically on dementia research, participants (particularly investigators and on-site researchers) were concerned about the place of dementia research in the landscape of public health and biomedical research. One investigator described it as "still the Cinderella group" because of the low priority put on social responsibilities towards older people. The (long-term) effects of Covid were recognised as an urgent priority for clinical research but there were concerns that this was overshadowing all other chronic illnesses:

> "Everybody has long dementia" … long COVID, obviously, is going to be a massive problem… but, yes, every person with dementia is facing that to a certain extent. **(Investigator, Clinical Research)**

The de-prioritisation bore out in practical ways, with researchers "trying to deliver the same studies in less time with less resources," in the words of one investigator. One facility the was "completely repurposed" by a vaccine study, meaning that the few screening visits had to be cancelled. This was described by an investigator as, "on the ground, the biggest issue to trying to deliver any studies, even when, nationally, you're able to."

In addition, investigators were extremely frustrated with the role of research and development (R&D) departments in setting up and maintaining non-Covid related trials and research studies in the UK, essentially shutting down research in every single other area. R&D departments were described as "glacial" due to the lack of responsiveness regarding dementia studies. This perspective contrasted with that of research assistants in the on-site group who believed that approach taken to speed up bureaucratic processes for Covid would have a knock-on effect for the dementia field.

Without belittling the urgency of Covid research, those responsible for running studies and raising the funds to do so wanted to highlight the ongoing, but perhaps neglected, need to develop treatments for dementia.

Questions for action/further research:

- What kind of partnerships can effectively and ethically support and secure a process of re-prioritisation of dementia research?
- How can we ensure ECRs don't "disappear" from the field of dementia research in the long term?
- Was the acceleration of digitising dementia research really "always going to happen"? Might there be a slowing down or reversal of these trends?

Impact on patients and participants: Inclusion and access to dementia research

Reducing the diversity of studies means reducing diversity amongst participants

A major topic of discussion amongst on-site researchers was around the impact of Covid on the diversity of studies being carried out and, as a result, the reduction of the "kinds of participants" able to access dementia research. Whilst much of this research was being

deprioritised due to its lack of 'direct clinical benefit', those studies that *might* prove clinically beneficial (e.g. treatment trials) were also being halted due to the risks of involving older or vulnerable people in face-to-face research.

Policies to pause studies focussing on older adults (over 50) were associated with the issue of neglected groups ("you would never say, 'we're going to shut down all the research for children,'" one investigator observed). This had very real consequences for the kinds of people who had access to research and who were coming through these research sites. Thus, whilst pre-Covid there was a broad mix of people with dementia or MCI and healthy controls, there were currently no "patient types" coming in. This has meant that only healthy volunteers have access to in-person research, whilst older, potentially more vulnerable populations can only take part in research offered remotely.

Risk factors for Covid and wider implications for participation: exclusion and 're-exclusion'

All discussions pointed to the implications of Covid for more indirect forms of exclusion, or "re-exclusion" as it was referred to in the investigators' group. The example of vaccine passports demonstrated this:

> Will that deter people who haven't had a vaccine from engaging in clinical services, engaging in research? What does that mean for groups in which there's not been a big uptake of vaccines? **(Investigator, Clinical Research)**

Cultural, religious, and ethnic minorities which have so far been less likely to be vaccinated, are already underrepresented in clinical research, as a **research coordinator** emphasised:

> I think there is a real risk to the generalisability of research studies. We are already terrible at it. We're really not good at engaging with the BAME community. All of these groups that are known to be high-risk.

'High-risk' refers to the complex set of issues that link cultural and ethnic minorities with the higher burdens of underlying health conditions and (therefore) Covid, *and* existing hesitancies to engage with clinical services. This researcher expressed concern about future research being about "the White middle classes" and not the "real UK population".

A set of interrelated issues emerged – primarily in the off-site group – around the possibility that technology could reduce issues around access and inclusion. Whilst remote technologies were put forward as potential solutions, there was debate around whether they could also further push people away who are less "technically with it and tech-savvy".

Insights from participants about access

On-site researchers cited practical and contextual factors affecting access from participants' and patients' own experiences. In London, this related to the reliance on public transport that was prohibited in lockdown, whilst at other sites, shielding participants would avoid taxis – "reinforcing the tendency to exclude that same group." This would be exacerbated by fears about visiting hospitals, even during times when visits were permitted, and research facilities deemed safe.

Despite all of this, however, levels of motivation to continue participation were generally observed to be high. This pattern bore out as expected for high intensity studies:

> "It's DFP, it's a lot to ask, so the vast majority are very, very, motivated" **(Research Coordinator, on-site)**

Hesitancy to attend visits from this group arose mostly from being needed as a carer for more vulnerable people. Those poised to go into drug studies from more vulnerable populations were equally keen to participate, even when this was prohibited.

Questions for action/further research:

- How can we avoid "re-excluding" already marginalised groups from dementia care and research, by managing the impact of Covid and its aftermath?
- What should the role of technology be in increasing inclusion?
- How will post-lockdown policies such as vaccine passports affect engagement with clinical research?

Practical and ethical challenges to conducting dementia research

This section draws primarily on the On-Site Researcher focus group, with additional insights from investigators, who had been working "on-the-ground" with participants virtually or in modified research facilities.

Managing dilemmas of clinical benefits, access to research, and Covid risk

The complex relationship between age, Covid risk, and dementia risk presented difficult practical and ethical problems to researchers. For example, negotiating the fact that people with dementia are more likely to benefit clinically from participating in trials but are also at high risk of contracting Covid:

> ...so, it has been a balance between, "These are treatment trials, we could open them, they could offer a lot of benefits." But we're bringing them into hospitals where they're doing massive amounts of COVID research as well - is that a good idea? **(Research coordinator, on-site)**

From a clinical care and assessment perspective too, there were dilemmas regarding risks relating to dementia and to exposure to Covid:

> There are people who get worse [with no contact], so I would ring them up and they can't walk anymore - they should have had their assessment intervention months back **(Research assistant, on-site)**

In most of these cases, both policies and researchers making on-the-ground decisions would almost always err on the side of caution when it came to Covid risk, but given the chance to reflect, there were serious concerns about the cumulative effects of this on participants, patients and research projects overall.

Challenges to maintaining communication, trust, rapport

When research was able to go ahead with certain populations, the precautions needed to manage the risk of Covid transmission presented material and practical barriers to communication and (potentially) rapport with participants, something that was extremely highly valued by researchers:

> On a personal, human, level it seems really crazy that we can't just offer someone a cup of tea because I think that is one of the basics of starting to build a rapport with someone, isn't it? **(Study doctor, on-site)**

Researchers were concerned that Personal Protective Equipment (PPE) would make communication more difficult, having an emotional and psychological impact on older participants for whom hearing and comprehension could be an issue and good rapport was essential. Researchers navigated challenges on a day-to-day basis and had lots of practical knowledge to share, for example around remote consenting. They also came up with creative ways to care for participants and maintain good communication during study visits. In one site, staff came up with a strategy of wearing enlarged photo ID badges so "there is a face behind all this PPE". Others reported advocating for safely serving refreshments and using screens instead of face-covering masks that would make some assessments untenable.

Questions for action/further research:

- How to close the gap between clinical work and research?
- Can we make research assistants/coordinators' practical and ethical work to maintain care for participants during Covid more visible and sharable across sites?

The role of remote testing and digital biomarkers, during and post-pandemic

We saw most divergence between groups on this topic, with on-site researchers and investigators expressing most concern or ambivalence about the possibilities and limits/dangers of digital and remote assessment methods. Perhaps unsurprisingly, off-site researchers were much more optimistic about the potential of measuring/predicting early dementia digitally, focussing on the need for more data to "improve and scale up validation" of these tools **(Bioengineer, off-site)**. However, all groups were concerned with using

technology to harness 'real world data' (although this meant different things to different people) and to predict, prognose and prevent dementia.

The need for remote methods during (and after?) lockdown

All groups discussed an increased need for remote technologies during lockdown. These ranged from simple telephone assessments, to online cognitive tests, to mobile apps, to wearable technologies for digital phenotyping. There were mixed opinions about whether digital and remote assessment methods for biomarkers and cognitive change were simply "better than nothing" during lockdown, or if they had real future potential. An industry partner emphasising the interest they have had in a remote digital cognitive assessment tool:

> [it has] a much larger potential to scale for the output of *whatever research they're doing* **(Industry partner, off-site)**

Another spoke about the imperative to have existing systems in place that can continue monitoring older people when face-to-face contact is not possible, using "wearable technology that can really measure things in real time continuously." **(Bioengineer, off-site)**

In contrast, on-site researchers discussed remote and digital testing methods as a necessity during the pandemic; "better than nothing" or "filling a gap" rather than desirable systems for the future. Another common concern was that tech was used to improve rather than reduce inclusion and access to prevention, clinical research and care for dementia. There was also tentative discussion about using technology to reduce socio-cultural 'gaps' between some populations and academic research.

Digital vs biological phenotyping: which is best for prevention?

"Deep" biological phenotyping was compared to more "frequent" or continuous digital phenotyping for the development of Alzheimer's disease and dementia. There was little agreement between discussion groups – or even amongst individuals within the investigators group – about whether "deep" or "frequent" aspects of phenotyping dementia should be emphasised in a post-pandemic world. Whilst there was a generally accepted usefulness of digital phenotyping over the past year there was some scepticism about this particular use of technology in the long term:

> I would, maybe, pivot towards using deep and maybe not-so-frequent phenotyping to help develop risk algorithms for predicting prognostication **(Investigator, clinical research)**

This contrasted with discussions in the off-site group, who were much more enthusiastic about the potential of digital tools for prediction:

> I think it's a lot easier to be able to detect risk with digital tools… it enables a more robust analysis of risk **(Industry partner, off-site)**

In this latter group, there was particular emphasis on the power of digital phenotyping for personalisation: to detect subtle *individual* changes, and intervene on this basis, rather than relying on more general biological thresholds. Those who considered digital phenotyping as "more personalised," also equated it with being the best route for prevention – "about delaying the age of onset rather than throwing more billions at drugs, I reckon" **(Digital health researcher, off-site)**. There was also a hope that digital phenotyping could offer more awareness of neurodegenerative conditions within individuals' lives, having an empowering effect, allowing them "to engage with it actively rather than leaving it until it really, really, does become a problem" **(Industry partner, off-site).**

However, even amongst proponents of digital phenotyping, there were some concerns about how effective it could be for prevention, firstly, due to the stigma of low digital literacy:

> You would feel, maybe, more stigma than you would if you were just to go face-to-face… If you're adding in the difficulties with tech, as well as difficulties with cognition, it might make it harder to overcome that felt stigma **(Industry partner, off-site).**

… and secondly, due to the stigma of cognitive signs of decline being attributed to 'the person' rather than 'the brain':

> I think it's funny that brain phenotypes are kind of seen as a bit of your identity in a way that physical health isn't… **(Digital health researcher, off-site)**

This participant saw a 1:1 relationship between the physical properties of the brain and the digital phenotypes and digital biomarkers – that this digital picture of pre-dementia can and should be something "to be worked on and improved". This contrasted with some perspectives in the on-site and investigators' group below.

Digital biomarkers: "a new way of measuring the wrong thing"?

Participants in the on-site groups expressed much more fundamental concerns with digital biomarkers than those discussed above:

> I mean, [digital biomarkers] are all bad… Alzheimer's disease is a brain disease, it is not a cognitive disorder. I think digital biomarkers are a new way of measuring the wrong thing **(Investigator, clinical research).**

This points to a key tension in how people conceptualise the object of dementia research, which the 'acceleration' of digital methods in biomedicine has brought to the fore. Whilst digital biomarkers were discussed in the off-site researcher group in terms of being "more personalised" and "empowering," other more clinic-based researchers had the opposite view, suggesting that the focus on cognitive function might make people *less* inclined to see dementias as preventable and (potentially) treatable, particularly when,

> There has been a big push to try to get people to understand that there is a *disease* that is underlying this process - not just "you're getting older and forgetful" **(Research coordinator, on-site)**

The concern here is that "the push towards wearables" might disrupt these researchers' wider project to frame Alzheimer's in particular as a "brain disease". Whilst there were overall differences between groups when it came to these key concerns, individual participants also held overlapping views about these contrasting models, reflecting the complexity of this ongoing debate.

Questions for action/further research:

- How do/will researchers reconcile contradictory views on dementia phenotyping in multidisciplinary projects?
- What is the role of social, emotional and psychological experiences of cognitive decline when measuring brain health?
- What is the relationship between 'brain health' and 'mental health'?

Take home messages for the future of dementia research

⇒ Clinical research is in a precarious position, but there is little consensus on where to focus efforts to collaborate and fundraise (e.g., with industry or the NHS) to keep research afloat and support early career researchers.

⇒ Dementia, and the populations it affects, needs to be re-prioritised[2] by changing current commitments/responsibilities towards older and more vulnerable populations *and/or* re-framing who 'brain health is for'.

⇒ On the one hand, studies with 'no clinical benefit' (e.g. DFP) have been de-prioritised to make space for trials that directly benefit older people (e.g., Covid trials). On the other, clinical trials for dementia treatment have been halted because of Covid-risk to older and clinically vulnerable people. This has widened the gap between research and clinical work in dementia.

⇒ Risk-averse decisions to protect vulnerable participants and patients from Covid can exacerbate or "re-exclude" already underrepresented groups in clinical research. There is a need for "noisy" data from people from diverse backgrounds with complex clinical histories.

⇒ Whilst research for over-50s was explicitly halted during the pandemic, other social, cultural, and ethnic groups have been indirectly excluded due to Covid restrictions. These indirect exclusions relate to other health burdens as well as limited access to clinical research, care, and technologies. The pandemic is therefore predicted to make dementia research less diverse.

⇒ Increased and accelerated use of new (digital and remote) technologies during the pandemic have exposed fundamental tensions in how people conceptualise the object of dementia research: as a 'brain disease' measured by 'deep' phenotyping or a cognitive condition that can be detected using 'frequent' phenotyping and identifying early digital biomarkers.

⇒ There is a shared desire to gather more 'real world data' on the early signs of dementia in future, but there is a lack of consensus about what 'real world data' is and how it should be measured. Can digital and clinic-based testing be brought together in integrated settings such as Brain Health Centres?

⇒ There is agreement about the point that 'prevention is better cure' when it comes to dementia – a message that has been amplified by Covid. However, there are split opinions about which model of phenotyping or assessment best enables prevention: digital phenotyping ('empowering' for the individual) or deep phenotyping (framing AD as a treatable brain disease).

⇒ Overall, these researchers are keen to harness technologies to address two key issues that have been made more visible and amplified by the Covid-19 crisis: the importance of early prevention and access to care and research. However, there was less agreement about *how* technologies for dementia assessment and phenotyping should be used, who they will benefit, and how older people might relate to them differently depending on their social situation and broader experience of (mental) health and care. These are urgent questions that should be addressed to create a more inclusive future of dementia research as we manage the effects of the pandemic.

References:

1. Cummings, J. *et al.* Re-Engineering Alzheimer Clinical Trials: Global Alzheimer's Platform Network. *J. Prev. Alzheimer's Dis.* **3**, 114–120 (2016).
2. Alzheimer Europe. *Alzheimer Europe position on supporting dementia research in unprecedented circumstances*. (2020).
3. Ulrich, C. M., Wallen, G. R., Feister, A. & Grady, C. Respondent burden in clinical research: when are we asking too much of subjects? *IRB* **27**, 17–20 (2005).
4. Bemelmans, S. A. S. A. *et al.* Psychological, behavioral and social effects of disclosing Alzheimer's disease biomarkers to research participants: a systematic review. *Alzheimer's Res. Ther.* (2016). doi:10.1186/s13195-016-0212-z
5. Milne, R. *et al.* Ethical Issues in the Development of Readiness Cohorts in Alzheimer's Disease Research. *J. Prev. Alzheimer's Dis.* **4**, 225–131 (2017).
6. Milne, R. *et al.* At, with and beyond risk: expectations of living with the possibility of future dementia. *Sociol. Health Illn.* (2018). doi:10.1111/1467-9566.12731
7. Milne, R. *et al.* Perspectives on Communicating Biomarker-Based Assessments of Alzheimer's Disease to Cognitively Healthy Individuals. *J. Alzheimer's Dis.* **62**, 487–498 (2018).
8. Bunnik, E. M., Richard, E., Milne, R. & Schermer, M. H. N. On the personal utility of Alzheimer's disease-related biomarker testing in the research context. *J. Med. Ethics* medethics-2018-104772 (2018). doi:10.1136/medethics-2018-104772
9. Karlawish, J. Addressing the ethical, policy, and social challenges of preclinical Alzheimer disease. *Neurology* **77**, 1487–93 (2011).
10. Molinuevo, J. J. L. *et al.* Ethical challenges in preclinical Alzheimer's disease observational studies and trials: Results of the Barcelona summit. *Alzheimer's Dement.* **12**, 614–622 (2016).
11. Padala, P. R., Jendro, A. M. & Padala, K. P. Conducting Clinical Research During the COVID-19 Pandemic: Investigator and Participant Perspectives. *JMIR Public Heal. Surveill.* **6**, e18887 (2020).
12. Alzforum. Coronavirus Takes Its Toll on Alzheimer's Clinical Studies. (2020). Available at: https://www.alzforum.org/news/community-news/coronavirus-takes-its-toll-alzheimers-clinical-studies. (Accessed: 1st December 2020)
13. Alzheimer Europe. *Alzheimer Europe: position regarding the allocation of scarce medical resources for intensive care services during the COVID-19 pandemic*. (2020).
14. Owens, A. P. *et al.* Implementing Remote Memory Clinics to Enhance Clinical Care During and After COVID-19. *Front. Psychiatry* **11**, 1–15 (2020).
15. Cuffaro, L. *et al.* Dementia care and COVID-19 pandemic: a necessary digital revolution. *Neurol. Sci.* **41**, 1977–1979 (2020).