How is dementia diagnosed during the pandemic? By Tom Russ, Heather Wilkinson, Katie Gambier-Ross, Denise Munro, Rose Vincent and Lindsay Kinnaird

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Dementia is a major public health issue with an estimated 885,000 people with dementia in the UK. Most people with suspected dementia are seen at a memory clinic where they will be told their diagnosis, however during the COVID-19 pandemic most memory clinics switched to remote consultations (often by telephone or video-call) to continue to meet the needs of patients while attending to infection control concerns. Although this rapid change to remote consultation was essential to minimise the risk of spreading the virus, little attention has been given to our three main areas of concern: the potential practical, ethical, and emotional impacts of this change.

1. Practical impact. Is it possible is it to assess someone remotely and are there risks of misdiagnosis?
2. Emotional impact. What is the impact of being told that you have dementia over the telephone, particularly at a time of social distancing from friends and family?
3. Ethical considerations. Is it ethical to deliver a dementia diagnosis in an uncontrolled environment?

While sharing the diagnosis is recognised as important, it has to be done sensitively and with appropriate support immediately afterwards and on an ongoing basis. Remote assessment may require use of technology that patients are not familiar with and careful consideration needs to be given as to how the access is made as simple as possible.” (Underwood et al., 2020, Providing memory assessment services during COVID-19. DOI:10.1080/13607863.2020.1830946).

There is a significant lack of clarity around how the person with dementia experiences the process of dementia assessment and diagnosis. Much literature on remote diagnosis is focussed on rural areas with little attention being paid to the lived experience of people living with dementia who are underrepresented in research, particularly in relation to receiving a diagnosis. A better understanding of this experience would enable personalised support to be delivered to people living with dementia during the remote diagnosis process. It would also empower professionals to deliver a diagnosis in a better-informed and empathetic manner.

Through understanding these experiences, the dementia diagnosis project will allow people with dementia to be better supported during the diagnosis process. Continuing to deliver diagnosis is vital to access appropriate care and support. Delivering diagnosis by telephone or video-call may be the “new normal” even post-pandemic, as we are predicting a shift toward remote and digital services.

Methodology

We will recruit people who have had appointments at memory clinics since the beginning of the first UK lockdown and staff from across the UK, making contact through existing professional networks as well as more broadly through social media. We plan to recruit approx. 30 people who have experienced receiving diagnosis remotely and approx. 30 members of staff with experiences of delivering remote diagnoses.

In order to foreground the experiences of people with dementia, we will draw on participatory approaches. We have established a PPI group of people with personal experience of dementia who will guide the research team. We will thematically analyse the interviews in consultation with PPI group and these will be used to inform an Online National Forum.

This Online National Forum will take place in phase two of the project and will bring together a wider range of stakeholders including people with personal experience of dementia, professionals and people working in dementia fields in an online consultation. The findings from the interviews will be presented at this event and discussions held to allow the participants to contribute to the outputs of the research project.

The online methodology used here means that the usual geographical limitations to implementing a project do not apply. We will be able to recruit people with dementia and memory clinic staff from across the UK, making our findings useful to a wider audience.

Timeline and Impact

The project began in spring 2021 and is expected to run for 12 months. We will have several outputs for the research to share the learning as widely as possible. This includes clinical guidelines for practitioners, a briefing paper for policy makers, academic papers to develop the evidence and a short animated film and podcasts targeted at a wider audience. These outputs will also be shared with the people who have contributed to the research through being a member of the PPI group, taking part in the online national forum or being interviewed for the study, as well as being distributed more widely.

Team

Tom Russ (PI) is an NHS Consultant Psychiatrist in old age psychiatry who works in a memory clinic in Edinburgh. He has experienced the change in services first hand and ′ to a limited extent ′ seen how people with suspected dementia have been affected. He is Director of the Alzheimer Scotland Dementia Research Centre (ASDRC) at the University of Edinburgh and Chief Investigator of the Lothian Birth Cohort studies. He is an experienced clinical academic with extensive experience of NHS clinical services and of research recruitment, assessment of capacity, and consent.

Heather Wilkinson (Co-I) is Professor of Dementia Participation and Practice and has worked for many years on research that intersects the methodological and ethical challenges of involving people with dementia in research, practice, and policy. She is a founder member of the Scottish Dementia Working Group, Director of the Edinburgh Centre for Research on the Experience of Dementia (ECRED), and Co-Director of the new Advanced Care Research Centre at the University of Edinburgh.

Katie Gambier-Ross is nearing completion of her PhD with ECRED. She is experienced in using innovative qualitative methodologies to understand the lived experience for people living with dementia. Katie recently worked on a project providing psychological support via a mobile application to persons living with dementia and their care partners during the COVID-19 pandemic.

Denise Munro is the administrative secretary for the ASDRC and is nearing completion of an MSc in Science Communication and Public Engagement at the University of Edinburgh. Having also worked as a research assistant, and with dementia patients in long term care, she has valuable expertise to contribute to the PPI aspect of this project, dissemination of results, as well as her essential administrative assistance.

Rose Vincent is an intern on the project and a PhD student in ECRED and the ASDRC. Her research is exploring volunteering in the context of young onset dementia and will address inequalities in access to volunteering. She is particularly interested in developing our understanding of how we can co-produce research with people living with dementia.

Lindsay Kinnaird is a Research Assistant on the project.