

Developing Poetry as a Research Methodology with Rarer Forms of Dementia: Four Research Protocols

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Abstract

People living with rarer forms of dementia tend to have progressive cognitive symptoms affecting skills other than memory and/or onset before the age of 65 years. They are often misdiagnosed and due to symptom profile or age of onset, do not usually fit well with care pathways designed for older people with typical Alzheimer's disease or vascular dementia. Although the arts have been increasingly used as interventions to support people with dementia, there is very little attention given to rarer dementia forms in arts and health research or practice. The objective of the present international study seeks to systematically explore four diverse forms of poetry writing within this population through virtual and in-person small and large group formats. Our approach includes investigating poetic processes as methodology through the lens of an arts-based methodological approach in order to explore how poems construct knowledge and a felt experience. We will also use more traditional qualitative approaches to understand the experience of writing, reading and listening to poetry as an intervention that can be used with different rarer forms of dementia. To the best of our knowledge, this will be the first study to explore poetry using multiple research protocols. The results will have implications for methodology development, co-constructed poetic inquiry and multiple opportunities for involving poetry in supporting people with dementia and family members.

Keywords

arts-based methods, young onset dementia, methods in qualitative inquiry, virtual environments, social justice

Approximately 50 million people worldwide have dementia caused by Alzheimer's disease, accounting for 60 to 70% of all dementias and affecting mostly people over 65 years (WHO, 2020). There are, however, other less known types of dementia with different symptoms disproportionately affecting those under 65. Harvey et al. (1996) defines rare dementia as having progressive cognitive symptoms other than memory and/or where onset occurs before 65 years. Non-memory-led dementias including conditions initially affecting vision (e.g. posterior cortical atrophy [PCA]), language (primary progressive aphasia [PPA]) and behaviour (e.g. behavioural variant frontotemporal dementia [FTD]). Hendriks et al. (2021, p. 1084) estimates an overall global age-standardised prevalence of 119.0 per 100,000 population in the age range of 30–64 years, corresponding to 3.9 million people aged 30–64 years living with young onset dementia in the world. Younger onset dementia presents a range of difficulties and issues for people

who are mostly of working age and are financially dependent on employment, may still have parenting responsibilities, provide care for older family members and remain too young for pension benefits (Cartwright et al., 2021). Obtaining

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statutory provision, in the United Kingdom (UK) for example, for respite and day care which is often geared up only for older people, is very challenging (UK Dementia Research Institute, 2021).

Lack of information and knowledge about rarer forms of dementia have often made the experience of obtaining an accurate diagnosis difficult and hindered finding appropriate care (Millenaar et al., 2016; Woolley et al., 2011), further complicating the lives of people living with rare dementias (PLWRD) and their care-partners (family members and close friends). Because of symptom differences and age of onset, providing support and care for this population through the same programming associated with Alzheimer's type dementia has proven problematic. For example, 'Memory Cafés' and other forms of charity-based support for older people with memory problems are not oriented for people who are at a younger stage of life and have different symptoms and concerns.

Poetry as an art, an intervention and a research methodology

Poetry as an art form likely predates written text (Bessinger, 2012) and can be traced to pre-historic African hunting, panegyric and elegiac court poetry (Finnegan, 2012). The *Pyramid Texts*, funerary poems for the pharaohs, have been identified as the earliest form of written poems from about 2400 BCE and found carved into interior walls of the pyramids at Saqqara (Allen, 2015). Chinese poetry from the *Book of Odes* has been dated to the 11th to 7th centuries BCE (Liu & Yucheng Lo, 1990) and other Asian written poetry traditions also have long histories (e.g. Korea, 1st BCE (Lee, 2002) and Japan 1stc CE (Konishi, 1984)). In Western poetic traditions, poetry began as an oral experience rather than a written one with the Iliad and the Odyssey initially recited aloud. The beginning of Western poetry is most often described as beginning with Homer's narrative poetry and Pindar's lyric style, around 800–200 BCE (Carey, 2020).

The arts have been increasingly seen as activities that can potentially enhance health and wellbeing, and there is growing evidence to support a range of art forms being used with different populations and age groups in community, clinical, hospital and residential settings (Clift et al., 2016). As an 'intervention', a term used more commonly by researchers than poets and other artists, participatory arts, including reading and writing poetry, have been seen as beneficial non-pharmacological (Zeilig et al., 2014) and collaborative interventions (Swinnin, 2016) that can improve mood, enhance relationships, reduce social isolation and provide sensory stimulation (Guzmán-García et al., 2013). In a small-scale exploratory study involving people with early stage dementia, poetry workshop participants identified writing poetry as supporting competence, self-efficacy,

personal growth and as a way to cope with disease progression (Petrescu et al., 2014). Poetry has also been used in different settings (Gregory, 2011), at different stages of dementia (Swinnen & de Medeiros, 2018) and with family caregivers (Kidd et al., 2011), providing multiple healthcare, education and public health intervention opportunities. A recent publication highlights the use of poetry by people with dementia, care-partners and family members, living in, working in and visiting care homes during the Covid pandemic (Living Words, 2021).

Considering poetic processes as a way to construct knowledge (Hanauer, 2010), poetry within dementia care research offers different methodological possibilities to use participant-voiced and researcher-voiced poetic experiences as part of analytic devices in data collection, as a way to present data in unique ways to bring new insights, and as a means of representing findings to peers and the general public (McCulliss, 2013, p. 88). Writing, reading and listening are different components of how poetry is experienced as an art form but these poetry components may also have methodological value. McNiff (2007) characterised the positioning of artistic processes and expression as a primary way of understanding lived experiences as part of arts-based research practice. As an arts-based methodology, poetic inquiry involves and integrates practice, process and product (Sinner et al., 2006), being both intervention and methodology. Developed, in part, from Alexander's (2003) discussion of aesthetic inquiry, the arts-as-methodology differ from most qualitative approaches (Camic, 2021) in that they go beyond being used only for data investigations that utilise more traditional descriptions and analyses of phenomena (McNiff, 2007, p.29) and (potentially) become 'about social justice and the control over the production and dissemination of knowledge' (Finley, 2007, p. 72).

Control over representation, production and dissemination of knowledge are important issues in dementia care research (e.g. British Psychological Society, 2016; Goodenough et al., 2017). How dementia is represented, characterised and narrated (e.g. as an older person's disease with memory loss as the main problem; as a syndrome that affects people from age 30 onwards) informs what kind of research questions are asked (e.g. How can we cure it? How can we provide lived experience support?), the types of research designs (e.g. randomised controlled trials comparing medications; longitudinal mixed-methods looking at models of support and co-constructed research designs) and the role of those affected by dementia (e.g. frail patient; activist). How *and by whom* messages about people with dementia and care-partners are narrated can impact the type of care and support available (Alzheimer's Society, 2017). The voices of those across the dementia spectrum can inadvertently be held silent by researchers, the general public, health and residential care policy and systems, but for those with rarer forms even obtaining a diagnosis can be very allusive (Sullivan, et al., 2021).

Study Objectives

As part of a wider research study that investigates support for rarer forms of dementia (Brotherhood et al., 2020), the present study seeks to examine how poetry and poetic inquiry can be developed methodologically to further understand the lived experience of rarer forms of dementia. Through ‘open-ended questions’ ... and ‘collaborative improvisation’ (Swinnen, 2016, p. 1378), across four different poetry research protocols, we will systematically explore:

1. How PLWRD and care-partners engage in the different protocols (e.g. how are the instructions and processes understood and what modifications are needed);
2. What knowledge is gained from PLWRD and care-partners about using different group approaches to create poetry (e.g. what is gained about the use of poetry, how is poetry useful, helpful, interesting, difficult, meaningless, insightful and worthwhile);
3. As research outputs (objects/products), how can the different protocols and resulting poems be used in dementia care, support and activism and
4. How might research-informed poetry engage professional education and public engagement and awareness about rarer forms of dementia.

Pilot Work

Piloting has been completed for protocols 1 and 2 (see below) with piloting for protocols 3 and 4 occurring in 2022.

Methodology

Bryman (2008) describes methodology as being ‘concerned with revealing in a systematic manner the practices of researchers and the ideas and presuppositions that lie behind those practices’. (p.167). The overarching methodological approach used across the four protocols in the present study incorporates both traditional qualitative approaches to analysis (Camic, 2021) and the use of poetry as an arts-based qualitative methodology (Daykin & Stickley, 2016). Art-based research is conceptualised in the current study as ‘a research method in which the arts play a primary role in any or all of the steps of the research method. Art forms [...] are essential to the research process itself and central in formulating the research question, generating data, analysing data and presenting the research results’. (Austin & Forinash, 2005; pp. 458–459). Poetry and poetic forms of inquiry were chosen because they allow immediate access to ‘a moment in time’ experience (Hadas, 2011; p.170), and ‘can provide a way of translating dense or abstract information into an easier format to process and connect with, especially for lay audiences’

(McCulliss, 2013; p. 109), whilst enabling individual and/or group participation longitudinally across the dementia journey.

Epistemologically, poetry like many of the arts, can produce different types of knowledge ‘that involve participating, creating, observing and responding... (through) a set of visual, kinaesthetic and auditory behaviours’ (Camic, 2008; p. 289). This raises questions for the present study about how to codify knowledge, what is knowable, what is worth knowing and what types of knowledge are we constructing *and for whom?* Our epistemological approach has been influenced by Berger and Luckmann’s (1991) social constructionism and Hammersley’s (1992) approach to realism where ‘reality is socially defined but this reality refers to the subjective experience of everyday life, how the world is understood rather than to the objective reality of the natural world’. (Andrews, 2012). For the present study, we are keenly aware that the dementias are biomedically characterised as a disease (an objective reality) but the experiences of living with different dementias (e.g. how to make sense of symptoms, daily life, disease progression and support needs) are constructed by those affected by dementia (e.g. PLWRD, care-partners, family members and friends) along with researchers and the research process. Each of the four protocols described below (and in further detail in Supplemental Material), explores different methodological approaches to knowledge construction through poetry.

Whilst poetry as an art form exists free from theoretical constraints, when used as a research tool, theoretical considerations become relevant as an exploratory means of trying to understand what we might be observing and learning. Theoretically, much of dementia care research appears underpinned by Kitwood’s theory of personhood and person-centred care (Kitwood, 1997). While this approach has partially informed the development of the present research, the limitations of Kitwood’s contributions have been noted (e.g. Higgs & Gillead, 2016) and revised (Dewing, 2008). Seeing PLWRD as ‘dementia activists’ (Bartlett, 2014a) and people who are active citizens (Bartlett, 2014b) also theoretically underpins the present study. In addition, lifespan developmental theories (Nyman & Szymczynska, 2016), which are particularly relevant to a younger dementia population are underutilised if not absent. Referring to Eric Erickson’s adult developmental theory, Clemerson et al. (2014) writing about young onset alzheimer’s describe, ‘The task for middle adulthood is generativity, which is defined by building a life, mastering a career and contributing to wider society and identity during this stage is primarily defined by work and relationships with others’ (p. 452). PLWRD may experience tasks at this stage of their lives disrupted and possibly no longer attainable. One question for this project is how poetry might capture these changes in a different way than a research interview and present them to different audiences.

Sampling, Settings and Recruitment

Sample

People living with a rarer form of dementia, care-partners and bereaved care-partners will be invited to participate. There are no general exclusion criteria or exclusionary medications for this study. The inclusion criteria are as follows:

1. Minimum age of 18 years old
2. Can understand and speak English or Welsh
3. Has the capacity to consent independently
4. Residing in the community and not in residential care or hospital
5. Access to the internet by computer, tablet or smart-phone and an email address

The approach to selecting a sampling rationale and determining an adequate sample size in qualitative research is not always presented transparently (Morse, 2015) and/or it is determined by a specific methodology (e.g. grounded theory uses saturation or theoretical sufficiency) rather than a sampling rationale that rests 'on shared methodological principles for estimating an adequate number of units, events or participants across qualitative methods' as Malterund et al. (2016; p.1754) suggest. The sampling rationale used in this study will be the same across all protocols. Participants will come from a sample identified with lived experience as a person with a rarer form of dementia or be a care-partner/family member. A definitive sample size for each protocol cannot be agreed a priori but will follow Malterund and colleagues (2021) information power (IP) approach. IP uses five dimensions (aim, specificity, theory, dialogue and variation) to determine ongoing sampling decisions, and based on these, we initially anticipate recruiting approximately 170 people across all protocols.

Settings

Those involved in the electronic poems (Protocol 1) will do so in their own residence with communication occurring by email. People involved in Protocols 2, 3 and 4 will meet in a designated community-based venue; data collection will occur onsite for these three protocols. At the time of writing this, as designated by national guidance in Canada, England and Wales, respectively, participants and group facilitators may be required to maintain social distancing, wear face coverings and use hand sanitiser upon entry to venues.

Recruitment Strategy

Participants primarily residing in England, Wales and in other areas of the United Kingdom will be recruited from Rare Dementia Support (RDS, n.d.), an organisation with over 3300 international members. Members will be contacted through

newsletters and email invitations. Canadian participants will be recruited by researchers from Nipissing University through posters and emails to healthcare professionals, dementia-related charities and public presentations and workshops.

Data Collection and Analysis

Piloting began in 2020 with formal data collection occurring between 2021 and 2023. Due to issues arising from the Covid-19 pandemic, it was decided to extend the electronic poems, which occur virtually, before commencing with the other protocols, all of which will occur in-person. An online qualitative survey using Qualtrics software will be sent to participants after the completion of each poetry protocol; surveys are specific to each protocol. For Protocol 1, however, the survey link will be sent after the completion of each poem (4 poems in total). Atlas.ti qualitative software will be used to assist analysis. The source material of poems (the original words provided by participants) will be initially analysed using thematic analysis (Braun & Clarke, 2006). Four researchers will independently line by line code all source material. A codebook will be developed based on iteratively coding 25% of the source material and used to further code all subsequent source material. For completed poems, the guiding arts-based research assessment (GABRA) meta-framework developed by Lafrenière and Cox (2012) will be used 'to assess the quality and effectiveness of utilising artistic works within specific research contexts' (p. 322). The GABRA framework will be uniquely used alongside thematic analysis to examine the completed poem and source material, respectively.

Protocol 1: The Electronic Poems

As the name implies, the electronic poems (Supplemental Material, pp. 2–5) are undertaken remotely. Initially developed as a protocol to involve people longitudinally, and living remotely or without access to rare dementia support groups, the pandemic obligated this protocol be implemented as the first and sole protocol for the first stages of the study. The development of these group-generated poems includes people across single and mixed rarer forms of dementia groups and experienced, consulting poets. Initially, piloting for Protocol 1, the electronic poems, was undertaken with our extended research team of 22 members, most of whom are not directly involved in the poetry component of the study; this has occurred over a 2-year period involving four poems. Initial feedback from PLWRD for Protocol 1 resulted in changes to the font type and size, the addition of an audio-recorded form of the completed poems and a change in presentation order of how information about the completed poems and source material was sent to participants.

After consenting to the study, participants are sent four different prompts at 4–5-week intervals. The first three prompts were developed by the research team in order to

explore if co-created poetry can contribute to our understanding of rarer forms of dementia. In the feedback survey for the third poem, participants will be invited to suggest topics for the final poem. Suggestions will be jointly considered by the poets and research team, and a final prompt will be agreed upon, taking into account, any common themes across and any particularly novel suggestions which may offer opportunities for the contribution of new insights.

Prompts for the first three poems:

1. What is your experience of having [e.g. PCA, FTD and PPA] or of being a family member caring for someone with PCA? (for the mixed rare dementia groups, the term ‘dementia’ was substituted for a specific diagnosis for prompts 1 and 2)
2. How would you describe [e.g. PCA, FTD and PPA] to a friend or family member?
3. What does support mean to you?

The involvement of experienced and published poets to help create poems from the words provided by PLWRD and care-partners is seen as a vital and differentiating part of this protocol. As one of four protocols and the only one where data will be collected electronically, the use of experienced poets will help to provide structure to many diverse voices who contribute source material. Although perhaps unusual in poetry, we see this as an opportunity for poems to be co-created by participants and professional poets (Zeilig, et al., 2018), and importantly, to solicit feedback from participants and poets about their experience writing words about highly emotive issues and then reading and listening to the poems co-created by participants and poets. A bound book of all poems, curated by the consulting poets, will be published and sent to participants and also distributed at nominal cost to the public and dementia professionals. The poetry collection will be launched during National Poetry Month in Canada and the United Kingdom and be available at: nationalbrainappeal.org/product-category/main-shop.

Protocol 2: Word-Exchange Poems

Word-exchange poems (Supplemental Material, pp. 5–6) are designed to be used in existing small group support meetings in different locations across England and Wales. All attendees will be invited to participate and data collection will occur after consent has been taken. This protocol is designed to allow group members to create poems in response to an issue of their choosing or alternatively, one the facilitator has chosen. Materials include a blank piece of paper, three Post-It Notes® or similar sticky note material and a pencil:

1. The activity begins when participants, responding to a prompt, write one or more different words on each sticky note. They will be encouraged to use all three notes, creating a ‘flash poem’ (A compact form of

poems that can be read in just a glance. Like senryus or haikus, authors can use just a few words to create a vivid picture).

2. After this is completed, one note is passed to the person on their left and one to their right, keeping one for themselves.
3. At this point, the prompt is repeated and people are asked to consider the words now in front of them and to arrange the sticky notes as they choose.
4. Volunteers are asked to read their poem out loud, followed by discussion. Alternatively, the facilitator can now collect the poems and read them, one flash poem at a time, leaving a moment or two pause between poems. It is important that all poems are read to give a sense of inclusion and value to all participants and to maximise participant engagement in research.
5. The facilitator collects all poems. Individual flash poems are typed-up as they were created. A second poem created by a professional poet brings participant words together to form one, continuous poem, which will also be audio-recorded.

Pre-pandemic piloting of the word-exchange poems (Supplemental Material, pp. 6–8), was conducted with an ongoing rare dementia support group. Asked to ‘Write about what makes you smile’, no difficulties were reported by volunteers and we were encouraged by them to use this protocol in further small group rare dementia support meetings. Comments included: ‘The poem is a bag of goodies that is sure to keep you happy and smiling, and sad things can be coped with better’; ‘I did not quite understand the title of the poem [*A Job Well Done*, titled by the consulting poet based on the source material] – I thought it was supposed to be about what made us smile but then I am not an expert in these things’; ‘It was interesting to see the commonalities brought together in the verses’.

Protocol 3: The Sequential Poems

The sequential poem protocol (Supplemental Material, pp. 6–8) was inspired by what is known as *The Exquisite Corpse* from the Dada art movement of the early 20th century (Breton, 1948; Kriss & Mulligan, 2013). This is the first time we are aware that it has been used in dementia-related research. This protocol was designed to allow PLWRD and/or care-partners to concurrently co-create a poem in a small group environment. Materials include a large, blank newsprint or other suitable paper (up to 60 × 85 cm), a soft tip marker (or pen) and a table:

1. The paper is placed on the table with the writing implement.
2. The group facilitator/researcher will write the first line as a prompt (e.g. What is it like to live with PPA? What do you continue to enjoy doing the most?).
3. The paper is then passed to the next person with the following verbal directions: Write one line responding

to the line immediately above; write what comes to mind, with the reminder that there are no incorrect responses. After this is completed, the facilitator turns down the page, leaving only the most recent line exposed. The paper is then passed to the next person with the same directions. This process continues until everyone has contributed ([Supplemental file](#), pp. 7).

4. Once all lines are completed the facilitator unfolds the paper and reads the poem first to him/herself, to get a sense of it and then aloud, pausing as one might when reading a poem; trying not to read too quickly so everyone can have the opportunity to hear it.
5. The completed poem is then placed back on the table and the group is invited to read and then discuss.

The poem will be sent to participants in typed-up written and audio forms, and an online link provided to complete a brief survey.

Protocol 4: Large Group Poems

Protocol 4 ([Supplemental Material](#), pp. 8–10) is designed for a large group format in order to obtain experiential information from many, but not necessarily all, group members. A large group for the purposes of the present study is between 20 and 70 people but this number can vary. Groups with many contributions will result in either one long poem with multiple verses or could be constructed as multiple poems grouped around themes/issues identified by participants. Those invited to take part will include people either in existing support groups (PLWRD and care-partners) or those in dementia-related public engagement and educational activities.

1. Information about the group poem activity will be sent in advance to group members as part of a regular newsletter. This will explain the poetry activity, provide the prompt to consider, and contact details of a research team member to answer any questions.
2. The facilitator on the meeting day (or a member of the research poetry team) will provide a brief introduction to the activity at the beginning of the meeting (a fuller introduction would have gone out in the newsletter). Two different options to participate will be provided.
3. On each chair, the prompt will appear at the top of a sheet of paper in 14-point Arial font. Participants will be invited to respond by writing their words on the paper and when done, to fold the paper in half. Responses will then be collected.
4. For those who prefer to participate at the break, a table with 2 researchers will be set up in a convenient but non-intrusive place. In order to accommodate people with diverse writing and reading abilities, volunteers will read out the prompt as the paper is given out and ask if the attendee would like to write out his/her response or would they prefer the volunteer to do so. They will be given a place to do this more privately.

5. Responses will be securely collected by volunteers. Over the course of about 1 week, researchers will meet along with a consulting poet, to bring attendees' words together as a poem or in the case of a very large group of attendees, multiple poems. The completed poem will be typed-up in 14-point Arial font and included in the next newsletter/email to members. An audio version of the poem will also be made available.

Attendees, once having read the poem, will be invited to anonymously respond to a brief online questionnaire in order to solicit feedback about the poem and process.

Ethical Considerations

The study has been approved by ethics committees at University College London (8545/004: Rare Dementia Support (RDS) Impact Study) and Nipissing University (10233: Rare Dementia Support Impact Study). Consent will be obtained through telephone or video interviews in order to involve a geographically diverse sample for protocols 1–3 (electronic and small group format). For informed consent to be obtained, there must be some form of clear affirmative action (positive opt-in); this cannot be inferred from silence, pre-ticked boxes or inactivity. In addition, we will adhere to Para. 26 (Declaration of Helsinki) which indicates that where obtaining written consent cannot be expressed in writing, non-written informed consent must be formally documented and witnessed. To achieve this, we will record the informed consent provided via telephone recordings and/or virtual face-to-face consent procedures via a secure and encrypted video platform (e.g. GoToMeeting) as outlined in [Brotherhood et al. \(2020\)](#). Ongoing determination relating to a participant's capacity to consent will be carried out in accordance with the Mental Capacity Act (MCA, 2005) and MCA Code of Practice ([Department of Constitutional Affairs, 2007](#)) with particular reference to assessing and obtaining ongoing consent for longitudinal elements (electronic poems). In Canada, the consent process is set out in the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS, 2018). Where a safeguarding concern is raised or identified in the United Kingdom we will follow the organisation's safeguarding policy and in Canada, guidance will be accessed from the relevant provincial or territorial adult protection agency. The need for further investigation or escalation will be managed in accordance with the safeguarding policy and in line with the Making Safeguarding Personal principles <https://www.local.gov.uk/msp-toolkit>.

Rigour, Quality Assessment and Reflective Practice

To encourage meaningful reflective practice, core researchers have been and will continue to participate in monthly meetings to discuss all aspects of the study; these meetings are recorded and transcribed. In addition to regular

meetings, staff involved in the wider research project will continue to participate in creating group research poems for reflective discussion throughout the project. Atlas.ti qualitative software will help provide an audit trail of all coding and analytic decision making. The Standards for Reporting Qualitative Research will be used to structure analyses and report results (O'Brian et al., 2014) to ensure validity and transparency.

Discussion

Poetry as an art form and as an intervention may be initially intimidating for some – as all the arts may be – but poetry is also highly accessible and has a long-acknowledged history, used internationally across different age groups and those with diverse cultural and ethnic backgrounds. A key concept in the development of the four protocols has been our consideration of the accessibility of distinctive poetry formats for people living with different rarer forms of dementia and their care-partners and family members, in rural and urban areas, as well as how to involve healthcare practitioners and academic researchers. Four protocols were established to explore how different delivery formats, group size, location and use of co-production with professional poets could develop poetic inquiry as a methodology, but also as an intervention, straddling arts-based and other qualitative research approaches. In the present study, creating poetry is also seen as a public engagement tool (Ball et al., 2021) to enrich perceptions and broaden understanding of the experiences and support needs of people affected by rarer forms of dementia. Information from our pilot studies has been encouraging but, as with many researchers, the Covid-19 pandemic and emerging variants have necessitated changes and alterations.

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Ethical Approval


The study has been approved by ethics committees at University College London (8545/004: Rare Dementia Support (RDS) Impact Study) and Nipissing University (10,233: Rare Dementia Support Impact Study).

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Supplemental Material

Supplemental material for this article is available online.

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