

Participatory Research Fund Project

Sustainable public involvement in music therapy and dementia care research: developing the Lived Experience Advisory Panel

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Overview:

Our research is focused on using music to support people affected by dementia. The Lived Experience Advisory Panel (LEAP) developed out of a group of experts-by-experience involved in a randomised controlled trial that tested music training in the community. From there, we were able to continue the work and formally establish the LEAP through the participatory research fund. Following a pilot of the group last year, we submitted a bid with the support of members. The LEAP has now become embedded in our music and dementia projects, across all stages of the research process, but with a particular focus on the funding application stage.

Aims and objectives:

The aims of this project were:

1. To support the development of a funding application to develop a novel music therapy intervention for people living with dementia in the community
2. To work towards sustainable, embedded public involvement in music therapy and dementia research
3. To expand LEAP to people affected by dementia from underserved populations, such as LGBTQ+, ethnic minority and young-onset dementia communities

Funding of £9,786 was used for:

- Paying for LEAP members' time to attend meetings and review documents
- Holding 1 hybrid meeting, to support travel costs and provide lunch
- Holding 2 online meetings
- A 1-day per week research assistant to support LEAP meetings and contribute to grant development



Do you want to know more or be involved?

Stakeholders involved:

People with the following experiences are involved in the LEAP:

- People living with dementia or mild cognitive impairment
- Those who are caring for or supporting someone with dementia
- Those who have experienced hospitalisations while living with dementia
- Those who have had challenges accessing dementia services or receiving a diagnosis

Patient and Public Involvement and Engagement elements:

- i) Advising on the development of new research ideas, specifically the types of music interventions and services needed across different stages of the dementia journey
- ii) Advising on ethical queries, such as the use of equipment or processes of engaging people with dementia in research
- iii) Reviewing and checking qualitative research findings related to music and dementia

Research outcomes:

Outcomes of this project are considered in relation to the three objectives identified:

1) Meetings with the LEAP group have contributed towards a grant application for developing a new multi-disciplinary intervention for people living with dementia in the community to prevent hospitalisation, in collaboration with NHS partners. For this project, working with LEAP helped us to:

- identify gaps in current UK dementia care provision,
- recognise the need for a proactive and preventative approach and
- consider potential challenges of engaging people affected by dementia in new services

2) Throughout the course of this project, we were able to continue to embed public involvement in music and dementia research projects. By having guest researchers join meetings, LEAP members could be involved in different stages of research projects, from development, to implementation to dissemination, as well as being involved in different areas that research relevant to individual experiences and interests.

3) In our final hybrid meeting with the LEAP group on this project, we plan to work with the group to consider ways of expanding the group to underserved healthcare populations, such as LGBTQ+, ethnic minority and young-onset dementia communities. This will inform the development of LEAP in a way that is co-produced and meaningful.

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