Research to help people navigate dementia services, to get the care and support they and their families need

Do you have experience of dementia or caring for someone who has? Could you help us to improve the research that we are doing into this?

About us:

We are a team of people with our own experience of navigating dementia services and researchers in health, social and community care systems. We are exploring how to improve the navigation of services by people with dementia and their families. Initially focusing on **Oxfordshire and Warwickshire**, we are working together with local stakeholders. We will be talking with people to find out about their experiences, what problems they have faced, and share ideas about what could help. From this small-scale research, we plan to develop a funding bid for a more extensive research project which would include trying out potential solutions.

Who we are looking for:

We are looking for people to join our Public and Patient Involvement & Engagement (PPI-E) Advisory Group. You may be living with dementia yourself, or have experience of supporting someone with dementia now or in the past two years.

You do not need to have any specific skills to join our research project – we are keen to work with people who have living experience of dementia and who are able to explain what that is like and contribute to our group discussions to help make our research project better.

We are able to pay PPI-E Contributors an honorarium. The rates are currently £40 for a 2-hour meeting including preparation and follow-up, together with up to £5 for expenses.

We will ask you to:

- 1. Take part in three meetings between February 2020 and July 2021, each lasting about 2 hours. Meetings will be on-line. There may also be times when we contact you for advice related to the research. First meeting: Mon 8th February, 2-4pm.
- Additionally, two PPI-E Advisory members will take part in up to three Reference Group meetings. The Reference Group will also be attended by individuals representing local health and social care providers and commissioners. First meeting: Wed 10th February, 9.30-11.30am.
- 3. **Read through documents related to the project** before or after our Advisory group meetings.

This research is funded by the University of Warwick

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Your contributions will be central to the success of this project.

What you can expect from us:

We can offer you:

- A phone conversation or online meeting to discuss questions you have about the project
- Opportunities to talk through and answer any questions, in confidence, before or after the PPI Advisory group meetings
- A final report of the outcome of the project, with your support credited.
- Opportunities to be involved in future research, if further funding is secured to expand the project.

For more information, and to join the Dementia Care Access Patient and Public Involvement Group, please contact:

- Dr Rene Wiedner at <u>Rene.Wiedner@wbs.ac.uk</u> or call 024 765 28619 / 07387 238359 or
- Dr Chris Lawes at chris.lawes@wbs.ac.uk

Project Team

- Dr Rene Wiedner (project lead) is an associate professor of management and organisation theory at Warwick Business School. He has published scientific articles on healthcare systems management, strategic change and innovation.
- Dr Chris Lawes (PPI-E lead) is a retired NHS consultant clinical psychologist whose father was diagnosed with dementia, and whose family's experiences of navigating services led to this project.
- Dr Alexander Komashie is a senior research associate in Healthcare Systems Design at the University of Cambridge Engineering Design Centre.
- Dr Anne-Marie Boylan is a departmental lecturer and senior researcher at the Nuffield Department of Primary Care Health Sciences, University of Oxford. Before his death, she supported her dad who had a diagnosis of dementia.
- Dr Stephanie Tierney is a senior researcher at the Nuffield Department of Primary Care Health Sciences
 at Oxford University. Her research focuses on long-term conditions, delivery of services and patients'
 experiences of care.
- Tamsin Jewell has extensive experience of delivering health, social and community care services, and has also supported family members with dementia.



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