

### What is Journeying through Dementia?

Journeying through Dementia is a large research study designed to find out whether attending a 12-week community programme assists people in the early stages of dementia to live as well as possible with the diagnosis. The study comes to an end in December 2019.

### How is the study going?

We have almost completed collecting data from all of the 480 participants who are taking part in the study all around England. We have just a few more follow up visits to complete during May 2019. We thank everyone who has participated in Journeying through Dementia.

### Experts by Experience Advisory Group

Working with researchers on the Journeying through Dementia study are a group of people living with dementia and family carers who form the study's Advisory Group. The work of the group is vital in ensuring the voices of people living with dementia are heard as this has always been a key focus of the study. Our Advisory Group members are from all walks of life and bring a wide range of skills and experience of dementia to the study. In February 2019 we held a data analysis workshop in Bradford with some members of the Advisory Group.



The purpose of the workshop was for advisory group members to give their views on quotes taken during interviews carried out by researchers with study participants.

Each quote was looked at separately by the group in turn, and group members gave their opinions on what they thought each quote meant. The quotes were then put into themes. For example, some quotes were about the content of the community sessions, some to transport and some to living with dementia.

All quotes were anonymised – so no one in the group knew who had said what, to make sure that each was treated as equally as possible. Working together to look more closely at the data has helped us have a better understanding of what study participants might have been feeling about taking part.

This study was funded by the NIHR Health Technology Assessment Programme (project number 14/140/80). The views expressed are those of the author(s) and not necessarily those of the NHS, the NIHR or the Department of Health.

Julie Hayden who lives with young onset dementia and took part in the data analysis workshop writes *“Always a pleasure to be meeting the team at Bradford, this occasion giving me the opportunity to meet with others living with dementia and their care partners in this friendly and welcoming group as part of gaining benefit from giving input. I would always encourage others to take up such opportunities. Thank you again for organizing the day and I look forward to the next time we meet.”*

## End of Study Event

To make sure that the results of the study reach as many people as possible and as a way of sharing our learning from Journeying through Dementia, we will be holding a final event known as a ‘Dissemination Event’ in Bradford on 6 December 2019.

Our Advisory Group will be working with us on this to ensure we do this in a way that meets the needs of people living with dementia and their families as well as others who may be interested. Invites will be sent out soon.

To help us make it as easy for people to understand the results of the Journeying through Dementia study and make it as interesting as we can, we are producing a film with our Experts by Experience. Watch this space for an update

## Summary of study results

A summary of the study results will be sent to everyone who has taken part in the study. We hope you find them of interest but get in touch if you don’t want to receive them using the email and phone number at the end of the newsletter.

## Here comes summer! (We hope)



The Journeying through Dementia team would like to wish everyone a happy summer.

## Contact Journeying through Dementia team

If you would like to get in touch or opt out of communications from the Journeying through Dementia study please contact us.

Email [JtD@sheffield.ac.uk](mailto:JtD@sheffield.ac.uk), or [jessica.wright@sheffield.ac.uk](mailto:jessica.wright@sheffield.ac.uk) or telephone Zoe Furniss on 0114 2159122.

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