



Participant Information Sheet

- **Project Title**

The lived experience of participating in church-based worship from the perspective of people with early stage dementia.

- **Research Purpose**

This research is being conducted for the dissertation project of Kathryn Baines for her Master's Degree in Occupational Therapy.

- **Research Aim**

This research aims to find out whether dementia affects people's participation in a church service.

Also, the researcher would like to know what things people with dementia find helpful when they are at church and what is unhelpful.

- **Your participation**

You have been invited to take part in this research because you have said that you have a diagnosis of early stage dementia and participating in a church service is important to you.

I would like to interview you to ask you about your experience when you go to a church service.

The interview will take place privately at your church or in a place where you feel comfortable.

You are welcome to have someone with you during the interview.

The interview will last for as long as you would like but be no longer than 45 minutes.



- **Benefits of participating**

There are no direct benefits for you personally, but your participation is extremely valuable and will help to contribute to evidence about how churches can become more dementia friendly.

- **Risks of participating**

There are no likely risks of participating. If, however, it makes you wish to further discuss your diagnosis, please contact your General Practitioner or to discuss matters regarding your faith, please speak to the church clergy.

- **Right to withdraw**

You can stop taking part in the research at any time, including before, during and after the interview.

You can ask for your data to be withdrawn up until when the data is analysed in March 2020.

You also have a right to not answer specific questions or to ask for audio recording to stop.

- **Privacy and Confidentiality**

If the interview happens in your church, this may mean that the church clergy will be aware of your participation.

I will write about what I find out in a report and I might also publish it in conference papers, journals and books.



I will share my findings within the community, at University and with other researchers.

However, your participation will be confidential.

Anything you shared during the interview will not be identifiable.

If you give consent, I may use direct quotes from your interview in public documents, however this will be anonymised.

- **General Data Protection Regulation**

The University of Plymouth is sponsoring this study.

The University of Plymouth will be using information from you in order to undertake this study and will act as the data controller for this study. This means that they are responsible for looking after your information and using it properly.

The University of Plymouth will keep identifiable information about you for 10 years after the study has finished, until 2030.

To safeguard your rights, we will use the minimum personally-identifiable information possible. The University of Plymouth will keep your name, and contact details confidential and will not pass this information on.

The University of Plymouth will use this information as needed, to contact you about the research study.



- **Who to contact**

If you have any questions, please contact me using the details below.



Name: Kathryn Baines

Email: kathryn.baines@plymouth.ac.uk

Phone: 07584168818

If you would like to withdraw or if you have any concerns, queries or complaints about this research, please contact my supervisor:

Patricia Eyres

Email: patricia.eyres@plymouth.ac.uk

Phone: 01752 587589

**Thank you for taking the time to read this information sheet. We
very much hope you will take part.**