



PARTICIPANT INFORMATION SHEET: The Ethics of Inclusion MA Research Study with Penny Pullan

Introduction

Before you decide whether or not to take part in this research it is important for you to understand why the research is being done and what it will involve. Please take time to read the following participant information carefully and discuss it with others if you wish. Ask me if there is anything that is not clear or if you would like more information, and feel free to have a look at the specific questions in the online questionnaire before committing.

Purpose of study

I am seeking to explore whether people of working age with invisible disabilities are included in their church communities in the Church of England. I'm focusing on people with long term chronic conditions that are not immediately obvious, including ME, Long COVID or people who are immunocompromised due to chemotherapy treatment. Their church community might include in-person, hybrid and/or online church. I wonder how much do these people feel they really matter and belong?

Why have I been invited?

You have indicated that that you have an invisible disability (a long term chronic condition such as ME/Long COVID, or you are immunocompromised due to chemotherapy), you are part of a Church of England community, and are between 18 and 65 years of age.

What will happen?

After reading this document, if you decide to participate, then go ahead and start the questionnaire. The first question will ask for your consent. The questionnaire will ask you questions about your experience of church. I recognise that inclusion can be a sensitive topic so you can choose to answer as few or as many as you feel comfortable.

The last question asks if you are interested in the possibility of a follow up interview with me. It asks for your contact details if so. This second stage consists of one Zoom interview, which will have a separate information sheet and consent form.

Do I have to take part?

No, participation is completely voluntary. You can withdraw yourself from the study at any time without any negative repercussions by emailing the main researcher, or expressing this during an interview.

You can withdraw your data from the study up until the point it has been anonymised, after this point it will be analysed and written into the research.

Will I receive any payment to take part in the research?

No, there are no direct payments or other financial benefits to taking part in the research.

Are there any possible disadvantages or risks to taking part?

The questions asked can be emotive and there is a possibility that you may find reflecting on your experiences of inclusion (or the lack of it) distressing. I suggest that you might like to arrange someone to talk to to support your participation in this study.

What are the likely benefits of taking part?

Some participants find that sharing their experiences can be beneficial. I hope that results from this study will help churches to better understand how to be truly inclusive for those with invisible illnesses.

Data Security for the Study

The data will be used anonymously in the MA thesis and could also be included for conferences and in publications. Your data will be stored securely on the laptop of the researcher and in the researcher's cloud space.

Anonymised quotes may be included in the MA thesis with your permission. If you wish, you can request to see anything published as a result of this study, whether the MA thesis or further publications based on this research.

Who is the researcher?

Penny Pullan, MA candidate at St Hild College, part of YTEP, studying for the Durham University MA in Theology, Mission and Ministry: penny@pennypullan.com

Penny is a Reader in the Church of England and her husband has suffered from ME for 33 years.

The supervisor for this project is Dr Sally Nelson.

How are participants selected to be part of this study?

There is an open invitation for people who meet the conditions of this study and live in England to apply to join by filling in the questionnaire. Please take part in the questionnaire directly, rather than via a carer.

Legal Statements

This study will have ethical approval from the ethics committee at YTEP, the Yorkshire Theological Education Partnership. This study will involve asking you for your contact information, religious views, experience of illness and experiences of church. Data will be stored and processed according to GDPR, and destroyed two years after the completion of the study. You are reminded that agreement to participate in the study does not affect your legal rights.

Contact details for complaints

If you have any complaints about the study, please feel free to contact me or my supervisor Dr Sally Nelson sally.nelson@sthild.org. If you feel unable to contact either of us or are unsatisfied with our response you can contact the Dean of Academic Studies at St Hild, Dr Justin Thacker justin.thacker@sthild.org

Taking part

If you decide you would like to take part, please indicate your consent in the first question of the questionnaire.