

# The Preferences of Older Self-funders in Navigating Community Social Care (The PRESENCE study)

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# Participant Information Sheet

**Purpose**

Older people who need social care, and informal carers, have to make important decisions when it comes to finding, choosing and arranging their services. This study is seeking to understand what help and support people most like when trying to navigate the care system.

**Why am I being invited?**

You may have experience that could help us further with this research. This might be because you already have experience arranging or organising care, or else because we are interested in what you might imagine would be important, should you ever find yourself needing care. Without hearing from people directly, there is concern that we might be missing important views.

**Who is doing the study?**

The study isled by an experienced team who work at the University of York.

**What will I be asked to do?**

Your participation would involve completing a questionnaire for us. This will include answering some questions about the things that are most important to you when navigating the care system. The questionnaire will take between 20 - 30 minutes to complete, and can be done on paper or online.

Your participation would involve a researcher posting a paper version or emailing a link to the online version of the questionnaire. The researchers would be available to provide support by telephone.

**Do I have to take part?**

No, participation is entirely voluntary. You do not have to give a reason. Whether or not you decide to take part will not affect any care you receive.

**What will happen to the information?**

All the information you give us is confidential. We will not discuss your details with anyone and we will not disclose to anyone that you are taking part. Reports from the research will not identify anyone who has taken part.

**Why should I take part in the project?**

By participating in this project you will help to inform the type of information and support that older people who self-fund prefer when finding, choosing and arranging their care. By doing this, we hope that in the future, self-funders and informal carers will be better supported in finding social care to suit their needs.

**Are there any risks to taking part?**

We do not think there are any significant risks to taking part. If you have had bad experiences of finding social care, it may be that the questionnaire prompts unpleasant memories. If you feel upset at any point please take a break or stop.

**What will happen to the results?**

When we have completed the research, we will produce a report of the findings. You will be sent a summary of the report if you are happy for us to do so. This report will also be sent to those who funded the research.

**Who is sponsoring the study?**

The study is being sponsored by the University of York.

**Who is funding the study?**

The National Institute for Health Research (NIHR) School for Social Care Research (SSCR).

**Does the study have ethical approval?**

The study has been approved by the NHS Health Research Authority (HRA) Social Care Research Ethics Committee.

**How will my data be processed?**

Please refer to the Data Information Sheet for an explanation of how your data will be used and protected, in line with General Data Protection Regulation (GDPR).

**What if there is a problem?**

If there is a problem at any time, please speak to the researcher about this. Alternatively, Dr Mark Wilberforce can be contacted using the details below.

**What happens next?**

A member of the research team will contact you to discuss the project with you further. If you then decide to take part, we will arrange a date to come to visit you.

If you would like to get in touch with us, please feel free to contact Rowan Jasper;
Email: rowan.jasper@york.ac.uk; Tel: 01904 321978 or Mark Wilberforce;
Email: mark.wilberforce@york.ac.uk; Tel: 01904 321297 at the Social Policy Research Unit (SPRU), University of York, York YO10 5DD.

**Thank you for reading this leaflet.**