

## Finding and Funding Social Care: the experiences of self-funders

### Information Sheet

#### What is the purpose of this information sheet?

This information sheet is an invitation for you to take part in a research study. Before you decide whether to take part, we would like you to understand why the research is being done and what it would involve for you.

Please read this information sheet. If you think you might want to take part, email or telephone me, Lyndsay Lindley, on [lyndsay.lindley@york.ac.uk](mailto:lyndsay.lindley@york.ac.uk) or 07552 285966 for more information about the study and for answers to any questions you may have. Feel free to talk to other people about the study if you wish.

#### What is the purpose of the research?

This research is about the experiences of older people who pay for their residential care or care at home. We usually call this group of people 'self-funders'. We want to find out what it's like to be a self-funder, starting with first realising that help is needed, deciding what amount of care is needed and choosing a care provider, through to self-funders' experiences of receiving care. At the end of the research, we will publish summaries, written, audio and film clips about these experiences on a new website called Socialcaretalk. This will enable self-funders to learn from people who have already been through this process.

We will also write research reports and papers, make presentations, and store the research data in an official archive so it can be used by other approved researchers.

We have been given approval by the Social Care Research Ethics Committee to do this research. This research is being carried out by the Social Policy Research Unit (SPRU) at the University of York in collaboration with the Universities of Oxford, Birmingham and Huddersfield. It is funded by the National Institute of Health Research, Research for Patient Benefit scheme (NIHR RfPB). The study runs from September 2019 until February 2021.

### **What will happen if I decide to take part?**

If you have experience of self-funding social care or are a relative or close friend of someone who is a self-funder, I would like to invite you to take part in a research interview. I will be interviewing a range of people with experiences of self-funding.

Your name has not been given to me so I will only be able to contact you if you email or phone me, Lyndsay Lindley at the University of York, my details are at the end of this information sheet. Or you can fill in the 'reply slip' and post it back to me.

If you think you would like to take part and you send me your contact details, I will contact you, answer any questions you have about the research and, if you do decide to take part, arrange a research interview at a time that suits you.

Owing to the Covid-19 pandemic, we have changed the way we are doing this study. To protect your health if you decide to take part, the research interview will be carried out via an online video call or by telephone.

### **What will the interview be like?**

Before we carry out the interview, I would like you to visit a website called '[Healthtalk](#)'. You will be able to see clips from people's interviews about health conditions. We'll be talking about social care not health, but the Socialcaretalk website will look very similar to [Healthtalk.org](#).

We will go through a consent form on the phone before the interview, and your consent will be audio recorded. I will ask if you agree to take part in an

interview and if you are willing to have our conversation filmed and audio-recorded. You will be given a copy of the consent form to keep.

The interview will be like a conversation. I will ask you to tell me, in your own words, about your experiences of social care, what your thoughts and feelings have been at different stages, how you got information, what you have done and what have been the good and bad parts of the experience.

### **How long will the interview take?**

The time it takes for an interview varies, depending on how much you have to say, but most interviews last at least an hour and often closer to one and a half hours. If you want to have a break, that's fine. You can also end the interview at any time without giving a reason.

### **What are the possible advantages or disadvantages of taking part?**

By choosing to take part, you will be contributing to research which will help self-funders and their relatives have access to a wide range of peer experiences of self-funding on a dedicated, publically available website. This website can also be used by professionals to learn more about self-funders' experiences.

After the interview, we will send you £20 as a thank you for taking part. We will also pay reasonable costs if you care for someone and need to make arrangements for their care during the interview.

Some of the things we talk about in the interview may make you feel emotional or uncomfortable. These will depend on your experiences, but may include your (or a relative's) care needs, financial issues or thinking about the future. On the other hand, talking about these things may make you feel good.

### **Do I have to take part?**

No. It is up to you to decide whether or not to take part. If you decide to take part, you can still choose to stop at any time, without giving a reason. If, following the interview, you decide to withdraw from the research, your information will not appear on the website. After the website is launched, we

can still remove your contribution but it may have already been widely viewed. Whatever you decide, it will not affect your care now or in the future.

### **What will happen to the information that is collected?**

In this research we will use information from you. We will only use information that we need for the research study. We will let very few people know your name and contact details and only if they need it for this study.

Everyone involved in this study will keep your data safe and secure. We will also follow all privacy rules. At the end of the study we will save some of the data for checking and future use by approved researchers.

All information which is collected during the research will be kept in line with the Data Protection Act 2018 and General Data Protection Regulations (GDPR). The study data may be looked at by people from the University of York for the purposes of audit.

In exceptional circumstances, we might have to tell someone else if you say that you or another person is being harmed. I will discuss this with you first.

I will label the interview recording with a code number. A transcriber will listen to the interview and type it up word for word. The transcriber will keep this confidential and will have signed a confidentiality, data storage and data transfer agreement with the University of York.

We will store the audio and film recordings and written account of the interview securely on university computers in separate folders to your contact details. Files will be password protected and only be accessible to the project team. Files containing personal data, such as your name and contact details, will be destroyed when the information is no longer needed for this study.

I will send you a copy of the interview transcript to help you decide whether you want your interview to be made available for our research, including on

the Socialcaretalk website and other audio-visual resources. I can make the transcript available in an alternative format if required. You will be asked to consider if there is anything you would like to change in the transcript and we can remove any sections you do not want us to use. You can take as long as you need to do this. You will have another opportunity to review how your interview is used on the website before it is launched on the internet.

### **What resources will you produce?**

If you do decide to allow your interview to be used for the study, it would be used along with interviews from about 40 other people with experiences of self-funding social care. We will analyse the interviews and write summaries of key topics that people talk about and make these summaries available on the Socialcaretalk website. People who use the site will be able to see these summaries as well as read extracts from the interviews and view the film clips of people who have agreed to these being shown.

### **Can I choose how my interview will appear?**

**You can choose whether a film, audio or written version of your interview is included.** I will ask you to sign a form 'Further use of my interview'. If you sign this form, you give copyright of the interview to the University of Oxford. It is important that you take time to think about and discuss the copyright form before you sign it. You will be given a copy of this form to keep.

If you do not want us to use your real name (first name only), you will be invited to choose an alias for yourself and others you mention in your interview, and you can keep out of the interview anything which might identify you. We will remove names, places and other identifiers from your interview, but it is possible that you may be recognised. **You should discuss this with members of your family since they might be connected to your appearance on screen.**

If you are recognised on a website, this would be a bit like appearing on TV. The material on the website is protected by copyright. This means that people are not allowed to copy or record what they find there, but it is possible that members of the public could copy and circulate extracts and images from the

website.. If you have any doubts about how you want the interview to be included, please talk to me.

### **To respond to this invitation**

If you are interested in taking part in a research interview or have any questions, please contact Lyndsay Lindley at the University of York, on 07552 285966, [lyndsay.lindley@york.ac.uk](mailto:lyndsay.lindley@york.ac.uk) or by post at Social Policy Research Unit, University of York, Heslington, York, YO10 5DD.

### **If I need to, who should I contact to complain about the research?**

Concerns or complaints about any aspect of the study can be addressed to Sally Pulleyn, Research Support Manager, by ringing 01904 321951 or emailing [sally.pulleyn@york.ac.uk](mailto:sally.pulleyn@york.ac.uk) or writing to her at Social Policy Research Unit, University of York, Heslington, York, YO10 5DD.

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## **General Data Protection Regulation (GDPR) Statement**

### **Finding and Funding Social Care: the experiences of self-funders**

The University of York is the sponsor for this study based in England. We will act as data controller for this study. This means that we are responsible for looking after your information and using it properly. As a university we use personally-identifiable information to conduct research to improve health, care and services. The legal basis for using your information for the study is 'task in the public interest'. We are working closely with the University of Oxford for this project.

#### **How will we use information about you?**

We will need to use information from you for this research project. This information will include your name and contact details. People will use this information to do the research or to check your records to make sure the research is being done properly.

People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead.

We will keep all information about you safe and secure.

Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

You will be able to choose how you want any research data to appear on the Socialcaretalk website.

Research documents with personal information, such as consent and copyright forms, will be stored together with the research data (interview recordings and transcript) securely at the University of Oxford – Nuffield Department of Primary Care Health Sciences for up to 100 years after the end of the study.

Your rights to access, change or move your information are limited as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible. You can find out more about how we use your information at: <https://compliance.admin.ox.ac.uk/individual-rights> or by contacting [ruth.sanders@phc.ox.ac.uk](mailto:ruth.sanders@phc.ox.ac.uk).

The University of York will use your name and contact details to contact you about the research study. Individuals from the University of Oxford and regulatory organisations may look at your research records to check the accuracy of the research study. The only people at the University of Oxford who will have access to information that identifies you will be people who need to contact you as part of your participation in this study or audit the data collection process. The University of York will keep identifiable information about you from this study in accordance with local policies.

### **What are your choices about how your information is used?**

You can stop being part of the study at any time, without giving a reason.

If you agree to take part in this study, you will have the option for your research data from this study to be used in future research. If you choose this option, your research data will be archived in the HERG Data Archive (<https://www.phc.ox.ac.uk/research/health-experiences/research-projects/news>) at the University of Oxford.

### **Where can you find out more about how your information is used?**

You can find out more about how we use your information:

- at [www.hra.nhs.uk/information-about-patients/](http://www.hra.nhs.uk/information-about-patients/)
- our project leaflet
- by asking one of the research team
- by sending an email to [lyndsay.lindley@york.ac.uk](mailto:lyndsay.lindley@york.ac.uk) or
- by ringing us on 07552 285966

If you wish to raise a complaint on how we have handled your personal data, you can contact our Data Protection Officer who will investigate the matter. If you are not satisfied with our response or believe we are processing your personal data in a way that is not lawful you can complain to the Information Commissioner's Office (ICO).

The Data Protection Officer at the University of York is Durham Burt,  
[dataprotection@york.ac.uk](mailto:dataprotection@york.ac.uk)