



Research Project: Care Confidence in Action

Information Sheet for people who have used Care Confidence



Hi, I'm Sarah. I work as a researcher at the University of York. You are being invited to take part in some research about the way [site] helps people to use Care Confidence.

Care Confidence is a website designed *with* and *for* older people who pay for social care to help you understand care options and make decisions. It is evidence-based and contains useful information for making a plan.

You are being invited to take part in some research about the experiences of people who may need to fund their own care (self-funders). This leaflet has more information about why we're doing this research and how you could be involved. It's up to you whether you take part. If you have any questions, you can contact me at sarah.brown3@york.ac.uk.

What is the research about? Understanding and arranging social care is not easy. Self-funders say they do not always know where to start or what their options are. Some would like help to make decisions and plan their next steps. At the [University of York](https://www.york.ac.uk/) we have developed a decision tool *with* and *for* older self-funders which is evidence-based and contains useful information to help people make a plan. The tool is called [Care Confidence](#). The council or organisation that told you about Care Confidence has developed a range of ways to support people to use it. We want to find out how well that's working and learn about your views and experiences of any support you received.

Why have you been invited to take part? You have been invited to take part in a short interview because we understand you have used, or were planning to use, Care Confidence to help you to make decisions about self-funded care.

What will taking part involve? You will be invited to take part in a conversation with Sarah Brown to talk about your views and experiences of using Care Confidence and any support you have had, or would have liked, with this. This conversation could take up to 1 hour, and can take place online, over the telephone, or face to face, to suit your preferences. With your permission the conversation will be audio-recorded to ensure we have an accurate record of your views. If you agree to take part, you will be asked to sign a consent form and you will be given a study number unique to you to ensure your information will be kept confidential.

Do I have to take part? No, you do not have to take part. Participation would be completely voluntary. If you choose not to take part, or if you choose to withdraw, this will not affect any care that you receive. You are free to change your mind about taking part at any time during the course of the interview without giving a reason and up to 2 weeks after the interview takes place. After that, it might not be possible, as your anonymised responses may already be included in the overall study findings.

What are the possible benefits of taking part? Research suggests that many people value taking part in research, as it is a chance to share their views and experiences in a way that may help others. Your participation in the study will directly help to shape our research findings, which may help other self-funders in the future. You will also be offered a £20 voucher in recognition of the time you gave up to contribute to the research.

Are there any risks to taking part? There are no perceived disadvantages or risks associated with taking part in the interview, other than the time it will take out of your day (between 30 minutes and 1 hour). You may feel uncomfortable talking about particular topics, such as your care needs or finances, or any stresses you have. However, you will not be asked to disclose any specific financial information. You are free to withdraw from the study at any time, without giving a reason.

The following sections tell you how we will use your data and keep it secure.

Will my taking part in this study be kept confidential? If you decide to take part in the study, what you tell us will be kept confidential and will not be shared with those involved in your care or treatment. No one outside of the research team will know that you have taken part in the study.

We will pay a transcription service to write a transcript of our conversation. They are bound by strict confidentiality agreements with the University so your information will be kept confidential. Data collected for the study may be looked at by authorised people to check

that the study is being carried out correctly. All have a duty of confidentiality to you as a research participant.

The only time we would break our duty of confidentiality is if we are worried that you – or someone else – was being, or was likely to be, harmed. If that happens, we will talk with you about it.

How will we use information about you? We will need to use information from you for this research project. This information will include:

- The information from our interview with you
- Your signed consent form
- Your name and contact details

People will use this information only to do the research or to check your records to make sure that 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.

The University of York is the sponsor of this research.

The University of York is responsible for looking after your information. We will share your information related to this research project with the following types of organisations:

- Other academic institutions requesting the study data for further research purposes. The data will not be used or released in such a way that you could be identified
- Restricted data may be shared through a data repository. Data will only be made available to authenticated researchers upon application, where the applicant's host institution has agreed to a Data Access Agreement which specifies how data may be used

We will keep all information about you safe and secure by:

- Allocating you with a unique study ID number which we will use to refer to your data when it is analysed and in any reports we produce.
- Securely storing study records on backed-up servers that are password protected and only accessible by members of the research team.
- Requiring third party professional transcribers to be bound by data protection compliant agreements to ensure that audio recordings are protected and only used for the purposes of producing the transcripts. Transcribers will be sent encrypted audio files, identified only by a code number, via a secure University file sharing system, with completed typed transcripts returned in the same way. The transcriber

will not retain the recording or transcript after it has been typed up and returned to the research team.

- Any identifying information in the audio recording will be removed from the transcript.
- Research records including your signed consent form will be securely stored for 10 years and then destroyed.

International transfers Your data will not be shared outside the UK.

How will we use information about you after the study ends? We will use an ID number to refer to your data when it is analysed and in any reports we produce. 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. We will keep your study data for a maximum of ten years. The study data will then be fully anonymised and securely archived or destroyed.

What will happen to the results of the study? The information collected will be analysed by researchers from the University of York. The results of the study will be published in academic journals and presented at conferences and webinars.

One way we can get the most benefit from this work is to make the study data available to researchers for related research at the end of this study. The study data may be reused by the research team or researchers in other institutions (on request) but will not be used or released in such a way that you could be identified.

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, but we will keep information about you that we already have.

You have the right to ask us to access, remove, change or delete data we hold about you for the purposes of the study. You can also object to our processing of your data. We might not always be able to do this if it means we cannot use your data to do the research. If so, we will tell you why we cannot do this.

Where can you find out more about how your information is used? You can find out more about how we use your information:

- At <https://www.york.ac.uk/records-management/dp/guidance/gdprcompliantresearch/>
- by sending an email to sarah.brown3@york.ac.uk
- by emailing the University of York's Data Protection Officer on dataprotection@york.ac.uk

What if there is a problem?

Complaints

If you have a concern about any aspect of this study, you should ask to speak to the research team who will do their best to answer your questions [sarah.brown3@york.ac.uk or lyndsay.lindley@york.ac.uk]. You can also contact the Chief Investigator, Kate Gridley [kate.gridley@york.ac.uk]. She will be happy to discuss your concerns. If you are unhappy with Kate's response, you can contact Professor Yvonne Birks [yvonne.birks@york.ac.uk], who is Head of the University of York's Older Adult's Social Care Research (OSCAR) Group.

If you remain unhappy following this and you wish to complain formally, please contact your local Patient Advice and Liaison Service (PALS) team:

Hull: hyp-tr.pals.mailbox@nhs.net or 01482 623065

North Yorkshire: tewv.pals@nhs.net or 0800 052 0219

York: yhs-tr.PatientExperienceTeam@nhs.net or 01904 726262

Data Protection

The University of York is the data controller for the information collected for this research, which means we are responsible for looking after your personal information and using it properly. If you are unhappy with the way your personal information has been handled, please contact the University's Data Protection Officer at dataprotection@york.ac.uk. If you are not satisfied with our response, you have a right to complain to the Information Commissioner's Office. For information on reporting a concern to the Information Commissioner's Office, see www.ico.org.uk/concerns.

Funding and ethical review: This project is funded by the National Institute for Health Research (NIHR) School for Social Care Research (Grant reference: NIHR-SSCR-CR13). The study sponsor is the University of York [michael.barber@york.ac.uk]. All documents and processes were reviewed and approved by the Health Research Authority (IRAS project ID: 356117).

Further information: For further information about the study, please contact Sarah Brown at University of York.

Email: sarah.brown3@york.ac.uk

Telephone: 01904 321263

Next steps: If you have had all your questions answered satisfactorily and wish to participate, please complete the consent form. You will be provided a copy of the completed form to keep.

How can I get involved in more research like this? If you would like to find out about other research projects you could be involved in, please visit [Involvement @ York](#).

Thank you for reading this information sheet