



PARTICIPANT INFORMATION SHEET INTERVIEW STUDY

You are being invited to take part in the above research study. To help you decide whether you would like to take part or not, it is important that you understand why the research is being done and what it will involve. Please read the information below carefully and ask questions if anything is not clear or you would like more information before you decide to take part in this research. If you are happy to participate you will be asked to sign a consent form.

Key points:

- We are a team of researchers who are looking into how we can improve the detection of urinary tract infections (UTIs) in people who live in care homes.
- We would like to learn more about your experience of being involved in the study.
- Taking part in the study would involve one interview with a researcher lasting no longer than an hour.
- Taking part in the study is kept confidential, and all interview transcripts are anonymised afterwards.
- You do not have to take part in the study if you do not want to.

1. What is the study title?

The full title of the study is 'Feasibility cohort study on predictors of diagnosis and prognosis of urine infection in care home residents.' However, we usually refer to the study by its short name which is DISCO UTI.

2. Who is doing the study?

The study is being carried out by a team of researchers from the University of Southampton, the University of Oxford and the University of Bristol, as well as other researchers from across the UK. We are interested in the health of older people who live in care homes.

3. What is the study about?

We are looking at how we can improve the detection of urinary tract infections (UTIs) in people who live in care homes. This is a common illness but it can be challenging for doctors to be sure whether someone in a care home has a UTI or not.

4. Why have I been invited to take part in an interview?

You have been asked to take part in this interview because you have been involved the DISCO UTI study – either as a family member, a consultee or a care home staff member.

5. Do I have to take part?

No, you do not have to take part if you do not want to.

6. What will happen if I decide to take part in the study?

We will arrange the time and date so that it is convenient for you. The interview could be over the phone or face to face depending on your location and/or preference. Before the interview starts you will be asked for your consent to take part in the study.

The researcher will interview you about your experience of working in a care home supporting DISCO UTI. They will ask a series of questions or prompts to help you. The interview will be audio-recorded on an

electronic Dictaphone. The interview will be in English. The consent process and interview should last no longer than one hour.

7. What will happen after the interview?

After the interview the audio-recording will be transferred securely to an approved professional transcription company, which has the facility to provide secure downloading of audio files and guarantees that information in the transcripts will remain confidential. The company will transcribe the interview and transfer it back to the research team. It will be checked against the original recording by a researcher and any information that could identify you will be removed. The anonymised transcript from your interview will then be compared to interview transcripts from other participants and analysed together.

8. What are the possible benefits of taking part?

There will be no direct benefit to you taking part in the research. However, the information gained from the study will be useful when planning further research in care homes, which may help care home residents and care home staff in the future.

9. Will I be reimbursed for taking part?

You will not receive any payment for taking part in this study.

10. Are there any possible disadvantages from taking part?

You will have to give up an hour of your time to take part.

11. Will my taking part in the study be kept confidential?

Your participation and the information we collect about during the interview will be kept strictly confidential.

Only members of the research team and responsible members of the University of Southampton and the University of Oxford may be given access to data about you for monitoring purposes and/or to carry out an audit of the study to ensure that the research is complying with applicable regulations. Individuals from regulatory authorities (people who check that we are carrying out the study correctly) may require

access to your data. All of these people have a duty to keep your information, as a research participant, strictly confidential.

12. What will happen to my data?

The University of Southampton conducts research to the highest standards of research integrity. As a publicly-funded organisation, the University has to ensure that it is in the public interest when we use personally-identifiable information about people who have agreed to take part in research. This means that when you agree to take part in a research study, we will use information about you in the ways needed, and for the purposes specified, to conduct and complete the research project. Under data protection law, 'Personal data' means any information that relates to and is capable of identifying a living individual. The University's data protection policy governing the use of personal data by the University can be found on its website (<https://www.southampton.ac.uk/legalservices/what-we-do/data-protection-and-foi.page>).

This Participant Information Sheet tells you what data will be collected for this project and whether this includes any personal data. Please ask the research team if you have any questions or are unclear what data is being collected about you.

Our privacy notice for research participants provides more information on how the University of Southampton collects and uses your personal data when you take part in one of our research projects and can be found at <http://www.southampton.ac.uk/assets/sharepoint/intranet/Is/Public/Research%20and%20Integrity%20Privacy%20Notice/Privacy%20Notice%20for%20Research%20Participants.pdf>

Any personal data we collect in this study will be used only for the purposes of carrying out our research and will be handled according to the University's policies in line with data protection law. If any personal data is used from which you can be identified directly, it will not be

disclosed to anyone else without your consent unless the University of Southampton is required by law to disclose it.

Data protection law requires us to have a valid legal reason ('lawful basis') to process and use your Personal data. The lawful basis for processing personal information in this research study is for the performance of a task carried out in the public interest. Personal data collected for research will not be used for any other purpose.

For the purposes of data protection law, the University of Southampton and the University of Oxford are the 'Data Controllers' for this study, which means that we are responsible for looking after your information and using it properly. The Universities will keep identifiable information about you for 10 years after the study has finished after which time any link between you and your information will be removed.

To safeguard your rights, we will use the minimum personal data necessary to achieve our research study objectives. Your data protection rights – such as to access, change, or transfer such information - may be limited, however, in order for the research output to be reliable and accurate. The University will not do anything with your personal data that you would not reasonably expect.

If you have any questions about how your personal data is used, or wish to exercise any of your rights, please consult the University's data protection webpage (<https://www.southampton.ac.uk/legalservices/what-we-do/data-protection-and-foi.page>) where you can make a request using our online form. If you need further assistance, please contact the University's Data Protection Officer (data.protection@soton.ac.uk).

13. What will happen to the results of this study?

We will publish the study findings through journal articles, reports, presentations and conference papers. We also hope to present the work to people who play an important role in care homes – like residents, staff and charities. We might use anonymised direct quotations from your interview in presentations and publications. You will not be able to be

identified in any written or verbal reports from the study. We will also send you a summary of the findings of the study if you would like this. Some of the research being undertaken will also be written up in a PhD thesis.

14. What if there is a problem?

If you have a concern about any aspect of this study, you should speak to the researchers (contact details below) who will do their best to answer your questions.

If you remain unhappy or have a complaint about any aspect of this study, please contact the University of Southampton Research Integrity and Governance Manager (023 8059 5058, rgoinfo@soton.ac.uk).

15. How have patients and the public been involved in this study?

Care home staff and relatives of those living in care homes have provided feedback on the design of the study and the information sheets that care homes and participants read. We will be asking for their help throughout the study, including how the results of the study are shared with care home residents, care home staff and the wider public.

16. Who is organising and funding the study?

The research is being organised by the Primary Care Research Centre at the University of Southampton and the Nuffield Department of Primary Care Health Sciences at the University of Oxford. The research is being funded by the National Institute for Health and Care Research School for Primary Care Research. Dr Abigail Moore is completing some of this work as part of her PhD which is being funded by the Wellcome Trust.

17. Who has reviewed the study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect participants' interests. This study has been reviewed and given favourable opinion by Newcastle & North Tyneside 2 Research Ethics Committee.

Further information and contact details:

Please ask the research study team if you have any questions or you do not understand the information we have provided on the contact details below:

Principle Investigator: Dr Abigail Moore

Telephone: 01865 289300

Email: discouti@phc.ox.ac.uk

Website: www.southampton.ac.uk/primarycare/disco.page#home

Thank you for reading this information and considering taking part in this study.