



Participant Information Sheet – Pharmacist, pharmacy staff or other healthcare professional interview

Study title: Community pharmacy alcohol-related liver disease risk identification and linkage to care through development of a complex intervention – The CIPLINC study

Researcher name: Dr Alexander Smith, Associate Professor Ryan Buchanan

ERGO number: 64726

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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. You may like to discuss it with others but it is up to you to decide whether or not to take part. If you are happy to participate you will be asked to sign a consent form.

What is the research about?

This study aims to develop a service in community pharmacies that can identify people who are at risk of alcohol-related liver disease and get them tested for it by linking with existing alcohol-related liver disease pathways of care.

The study aims to better understand how the service could work, This will help design it before testing it on a small scale. If it is successful, we plan to roll it out more widely. This work is being done as part of a PhD qualification and is funded by the National Institute for Health Research (NIHR).

In the long term we aim for the service to help increase earlier diagnosis of alcohol-related liver disease. Earlier diagnosis can prevent patients with the disease from developing harmful complications.

Why have I been asked to participate?

To understand how the service could work we would like to interview community pharmacists and pharmacy staff and healthcare providers involved in pathways of care for patients with alcohol-related liver disease.

What will happen to me if I take part?

If you take part, you will be asked to have an interview with a researcher for which we will record the audio. This can be done face-to-face, by telephone, or online depending on your preference. The interview is expected to take 30 minutes. In the interview you will be asked your thoughts on how community pharmacists could identify people at risk of alcohol-related liver disease and connect them with existing pathways of care. The interview will also explore potential barriers and facilitators to this.

Are there any benefits in my taking part?

To reimburse you for the time you have taken to participate in the interview you will be offered a £20 shopping voucher. Your involvement will also contribute to improving the service.



Are there any risks involved?

We believe this study is low risk but we know research interviews can sometimes bring up difficult or sensitive issues. If this was to occur the research team will endeavour to help or refer you to those you can. This would be done with your consent. We would only disclose information to someone outside the interview without your explicit consent if we felt there was a risk of harm to yourself or other people.

What data will be collected?

As well as the recorded interview the research team will record your age, sex, job title, years in current job position and category of your place of work.

Will my participation be confidential?

Your participation and the information we collect about you during the course of the research will be kept strictly confidential.

After the interview the recording will be uploaded on the same day onto secure computer network storage at the University of Southampton. The recording will then be deleted from the recording device. The recording will be transcribed by a member of the research team or by a university affiliated transcription service. Any potentially identifiable information (e.g. locations, names) will be anonymised in the transcript. The original recording of the conversation will be kept for up to 12 months before being destroyed.

Data collected will be stored on secure computer network storage at the University of Southampton or in a locked room at the University of Southampton where on paper (e.g. your consent form if not done electronically). Your data will be recorded under a unique code number. The linking data between your name and the code number will be kept separate from the rest of your data. We will keep all information about you safe and secure

Only members of the research team and responsible members of the University of Southampton 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.

Do I have to take part?

No, it is entirely up to you to decide whether or not to take part. If you decide you want to take part, you will need to sign a consent form to show you have agreed to take part.

What happens if I change my mind?

You have the right to change your mind and withdraw at any time without giving a reason and without your participant rights being affected.

You can withdraw from the study up to 1 week after the interview and we will not use any of the information you provided. If you withdraw from the study after this we will use the information provided only for the purposes of completing the project but will not use any direct quotations from you in any research reports or publications.

If you wish to withdraw you can contact us using the details provided under 'Where can I get more information.'

What will happen to the results of the research?

Your personal details will remain strictly confidential. Research findings made available in any reports or publications will not include information that can directly identify you without your



specific consent. We will publish quotes from the recorded interviews but you will not be directly identifiable from these quotes.

Where can I get more information?

If you wish to take part or would like more information please contact Alexander Smith.

He can be contacted Monday-Friday 9am – 5pm on 07385 874065 or via email: ciplinc@soton.ac.uk

Alternatively Associate Professor Ryan Buchanan can be contacted on: 02380 7776742

What happens if there is a problem?

If you have a concern about any aspect of this study, you should speak to the researchers 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).

Data Protection Privacy Notice

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 is the 'Data Controller' for this study, which means that we are responsible for looking after your information and using it properly. The University of Southampton 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.

All personal data collected for the research will be pseudonymised using a participant identification number. Only members of the research team will have access to the linking data between participant name and their identification number, which will be kept separate from the pseudonymised data.

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).

Thank you for taking the time to read this information sheet and considering taking part in the research