

Patient Participant Information Sheet

SEQUENCE Digital: Sexual health equity through evidence-based online clinical care – Pre-Trial Qualitative Studies.

Study C Interviews

Version 2; 23.06.21

Introduction

The aim of this study is to understand what people think about using an online service for receiving STI (sexually transmitted infection) test results, accessing treatment and telling partners about a result. We want to better understand what people think about using this kind of online sexual health service and how we can improve the service so it is something that people would want to use.

We are looking to interview people who fit the following criteria:

- 16 years of age or older
- Recently been diagnosed with a bacterial STI (e.g. chlamydia or gonorrhoea) or recently been told that a partner has been diagnosed with a bacterial STI (e.g. chlamydia or gonorrhoea)
- are able to understand what the study is asking from you and to consent to this
- are able to read and speak English well enough to participate in an interview

The study is being led by the SEQUENCE Digital ('Sexual health equity through evidence-based online clinical care') research team at Glasgow Caledonian University (GCU) and University College London (UCL) (IRAS no. 299331). Central and North West London (CNWL) NHS Foundation Trust is the study Sponsor in collaboration with researchers at GCU and UCL. The team at UCL is leading all the work being done in this particular study. The study is being carried out as part of a larger research project which aims to improve access to online sexual health services and to develop an online system to support people who are testing for STIs and their partners. GCU is providing indemnity for the SEQUENCE Digital project. CNWL NHS Foundation Trust is the data controller and Professor Claudia Estcourt, the Chief Investigator, is the data custodian.

Before you decide if you want to take part, it is important for you to understand what participation in this study would involve. Please take time to read the following information carefully and discuss it with others if you wish. Please contact Roos Van Greevenbroek ([nhs.net email of researcher](mailto:roos.van.greevenbroek@nhs.uk)) if you would like more information.

Why is the study important?

This study is important because it allows people who are users of sexual health services the opportunity to tell us what they think of using an online service that can tell them the results of their STI tests, and if needed, allow them to access treatment and tell their partners online. We want to know what would make people more likely to use this kind of online service and how we can improve it. The findings of this study will help us to develop an online platform to support people who are testing for and receiving treatment for STIs, which will then be tested in a larger study.

What will I be asked to do if I take part?

In an interview with a researcher, you will be asked questions about your experiences using sexual health services, including online services, if you've used them. You will also be asked what you think of using an online system that helps people to receive the results of STI testing, to access STI treatment through an online prescribing service, and to tell their partners about their diagnosis. The researcher will talk to you about what you think would make it easier for you to use an online service like this and what would make it harder. At one point in the interview, the researcher will share an example of what this online system could look like and ask you what you think of it.

You do not have to answer any questions you do not want to and can choose to take a break or stop the interview at any point without giving a reason. The interview should last about 60 minutes. You will also be asked to complete a short online questionnaire that will tell us a bit more about you. The link to this questionnaire will be shared with you during or just after the interview. In this questionnaire, you will be asked to share some information about you and your personal circumstances (e.g. age, gender, ethnicity, sexual orientation, ethnicity, the country where you were born, any disabilities, relationship status, highest qualification, employment status, postcode, your internet use, and use of sexual health services and online health care).

The interview will take place by phone call, audio/video call using a messaging service (e.g. WhatsApp, etc.), or video conferencing service (e.g. Zoom). The interview may also take place in person, if you and the researcher decide this is the best option and local COVID-19 restrictions permit. The interview can take place at a time convenient to you and the researcher. The interview will be audio-recorded and then transcribed for analysis by a professional transcription service. This professional transcription service has signed a confidentiality agreement with our study and will keep the information you share with us secure.

At the end of the interview, you will be offered a £30 gift voucher to reimburse you for your time. The voucher code can either be sent to you via email or encrypted messaging service (e.g. WhatsApp), or a paper voucher can be sent to you by post. You will also be sent information telling you about some psychological and sexual health support services in your area. This will be sent regardless of whether any difficult issues arise in the interview.

Do I have to take part?

No. You decide if you want to take part in the study. You can stop the interview at any point without giving a reason. You can also ask for your interview or questionnaire answers to be deleted at any time up until the study closes and no further data is being collected (approximately December 2021).

What are the possible risks of taking part?

We think that it is unlikely that you would come to any harm through taking part in the study. In the interviews, you will be asked about your experience of using sexual health services. This could potentially bring up unpleasant memories or experiences. The researcher conducting the interview is experienced in talking with people about these topics and will support you during the interview, if you do become upset. You do not have to answer any questions you do not wish to, and you can take a break or stop the interview at any time. If you decide to stop the interview, it will not affect any NHS services you are receiving or will receive in the future. You will also be provided with a document that details psychological and sexual health support services local to your clinic at the end of the interview. There is a risk that the researcher may have to break your confidentiality to tell someone about what we discussed in the interview, if it is necessary to protect your or another person's safety. Whenever possible, the researcher will discuss this with you first.

What are the possible benefits of taking part?

We can't promise that the study will help you personally. However, the results should improve our understanding of how best to deliver an online sexual health services in the UK. This, in turn, could benefit the people who go on to use these and other online services.

What happens when the study stops?

After the interview, the audio recording will be turned into a written document by a professional transcriber who has signed a confidentiality agreement. The audio recording and transcript will be pseudonymised; this means it will be identified using a code number and not your name or any other personally identifiable information about you.

Once your transcript is returned from the professional transcription company and checked for accuracy, we will destroy your interview recording audio file. Your contact details, which will be held separately to the rest of your information, on secure NHS computers and within the encrypted @NHS.net email service, will be destroyed at the end of the study (anticipated April 2022). We will keep your verbal consent recording, transcript, demographic information on secure UCL servers under password protection for a minimum of 10 years. Only members of the research team will have access to this data. Other researchers employed by the universities affiliated with the SEQUENCE Digital project and students studying on courses at these universities may request to access this data through the Chief Investigator, who is responsible for how the study is conducted. Access to this anonymous data will only be permitted if you have explicitly consented and if it is appropriate for their research.

Interview transcripts will be transferred between the research team via email for analysis and cross-checking purposes. We will then analyse your transcript along with those of other participants and share our results in a number of ways. The findings may be presented at different events to let people know what we found in this study. The findings will also be written up and submitted for publication in academic journals and presented at scientific conferences. We will not include any identifiable information about you in our presentation of these findings. If we use a quote of something you said during our interview, you will only be identified using a pseudonym. These findings will be used to inform the development and refinement of an online STI testing and treatment service. A copy of any of our publications can be requested from Roos Van Greevenbroek ([nhs.net email of researcher](#)) and will be made available on our study website (www.sequencedigital.org.uk).

What if there's a problem?

If you are concerned about your participation in the study and would like to speak with someone within the study team, please contact Dr Jo Gibbs (jo.gibbs@nhs.net) or the study sponsor, CNWL NHS Foundation Trust (sponsor.noclor@nhs.net). You may also contact the Patient Feedback and Complaints Service for CNWL NHS Foundation Trust (email: feedback.cnwl@nhs.net and telephone: 0300 013 4799).

How will we use information about you?

We will need to use information from you for this study. This information will include:

- your first name and last name.
- your phone number and/or email address.
- your clinic number.
- your age, gender, ethnicity, sexual orientation, ethnicity, the country where you were born, any disabilities, relationship status, highest qualification, employment status, postcode.
- your sexual behaviour, lifestyle and use of sexual health services.

People will use this information 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, linked to your clinic number in a study log stored on a secure UCL server that requires password access. 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.

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. You can choose to have your data removed from the study up until we stop collecting new data (December 2021). After that, we will not be able to remove your data and we will keep information about you that we already have.
- We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

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/.
- our leaflet available from www.hra.nhs.uk/patientdataandresearch.
- by asking one of the research team [Study C researcher NHS email address].
- by sending an email to the Sponsor's Data Protection Officer (cnwl.dpo@nhs.net).
- by ringing us on [Study C mobile phone number].

Who has reviewed the study?

All studies involving human participants are reviewed by an ethics committee. The role of the ethics committee is to protect the safety, rights, wellbeing, and dignity of study participants. This study (IRAS no. 299331) was reviewed by the East of England - Cambridge South Research Ethics Committee and given ethical approval on 29/06/21 under the following approval code: 21/EE/0148.

How do I make contact with the study team?

If you have any questions about the study, please email Roos Van Greevenbroek at: [researcher's nhs.net email address]

What happens next?

The study team will contact you to ask if you are still interested in taking part in the study, check you are eligible to participate, and arrange an interview.

Thank you for taking the time to read this information.



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