

Experiences of COVID-19 Epidemic: a qualitative study of people living with, affected by, or working in HIV in the UK

Participant Information Sheet

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish.

Part 1 tells you the purpose of this study and what will happen to you if you take part.

Part 2 gives you more detailed information about the conduct of the study

Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for reading this.

What is the purpose of the study?

This study aims to explore the experiences of people living with, affected by, or working in HIV during the COVID-19 epidemic and to use this to inform current policy.

Why have I been invited?

You are being invited to take part in this study because you are someone who supports people living with HIV (either as a health, social care, charity or community worker), are aged 18 or older and has experiences of the COVID-19 pandemic. We hope to conduct between 10-15 interviews initially and then interview people living with, and affected by, HIV in a larger study.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a consent form online. You are free to withdraw at any time and without giving a reason.

What would I have to do?

This study involves filling out a short questionnaire and being interviewed at two time points (once at the start of the study, and a second time 3-months after the first interview). Because of the pandemic, the study is being conducted digitally using Microsoft Teams or by telephone.

The confidential online questionnaire asks basic demographic information. This data will be aggregated to describe the sample of participants and will be used to ensure that we have reached a diverse group of people.

We will use the interviews to conduct research focused on understanding how people living with HIV, and HIV services, are currently being impacted by the pandemic, and we will use this information to inform research design and policy development. We will ask you to consent to participating in the study through Qualtrics, an online platform used for surveys by Imperial College. Where not possible, we will ask for consent verbally.

If you agree to be interviewed, you will be contacted by email or telephone to discuss the study further and arrange your participation. We expect interviews will last between 60 and 90 minutes and will be informal. We will ask you to reflect on a series of questions about the COVID-19 epidemic. The interview will be conducted on Microsoft Teams and will be recorded. For participants who do not have digital access to Microsoft Teams, we will conduct and record interviews over the phone, and where not possible to consent via Qualtrics, we will ask for verbal consent from participants at the beginning of the interviews. Over the course of the interview, you may refuse to answer any question at any time. You may also retract your consent during the research process and any time after this research is completed.

We will also give you the opportunity to be re-contacted, so that we can keep you updated with the progress we make, should you consent to this.

What will happen to me if I take part in the interview?

You will sign an electronic consent form via a link in the invitation email via ticking a box on the form.

Participants will be invited to contribute to one or more of these procedures:

- 1) Participants will be asked to fill out a confidential online questionnaire with basic demographic information. This data will be aggregated to describe the sample of participants and help us to select a diverse group to be invited to be interviewed.
- 2) Some participants will be invited for a video-chat interview with one of the researchers. Over the course of the interview, you may refuse to answer any question at any time. You may also retract your consent during the research process and any time after this research is completed.

The interview will be a little like a conversation, in which I will help you talk about yourself in your own words. Issues we would like to discuss include work life, family life, friendships and social connections and the impact of COVID-19 on HIV care. We will also be inviting living with HIV (and their carers) to take part in a separate study.

What are the possible disadvantages and risks of taking part?

There are no particular disadvantages to taking part in the interview. You may be asked about sensitive information, such as your health status. If you feel uncomfortable with any part of the interview conversation, you can refuse to answer any question or ask for part of the conversation to be removed from the transcript. You may feel inconvenienced by the time required as the entire interview process will require approximately 60 to 90 minutes. Finally, given the general public anxiety surrounding the outbreak, answering some of the questions may cause distress. A list of useful resources are given in an attached PDF handout.

What are the benefits of taking part in the interview?

You will not derive a particular benefit from participating in the interview, though many interview participants find the opportunity to discuss their experience to be satisfying or therapeutic. As researchers, we hope that your participation offers an opportunity for reflection. We expect that your perspective, alongside that of others in this study, will be of great value in developing public health policy now and in the future.

What does taking part in the interview involve?

Taking part involves an interview with a qualified interviewer. It takes approximately 60-90 minutes to complete. If, when doing the interview, a topic of conversation arises that makes you feel uncomfortable, you can let the interviewer know that you wish to move on to another subject or terminate the session altogether. It is important for you to understand that you are not required to discuss anything that you do not want to.

What if I decide to withdraw after the interview has taken place?

You are free to leave the study at any time. If you decide to leave after an interview has taken place, all recordings, transcripts and typing of your interview would be destroyed. You can request to leave the study by emailing or telephoning the research team.

What would happen after the interview?

The interviews are recorded and transcribed using an automated, in-built Microsoft Teams transcription service. We will record the interviews to ensure we do not forget or miss important information that you tell us. No identifying information, such as your name, would be kept with the interview transcripts and the interview recordings, and only people in the research team would have access to them subject to participant's agreement. The digital recording and the digital typed up record (transcript), identified only by the code number, would be kept on secure servers at the Patient Experience Research Centre at Imperial College London.

How would the researcher use the interview recording and transcript?

If you do decide to allow your interview to be used for the research study, they would be used along with interviews from between 10-15 other people working in areas supporting people living with HIV. We will use these in two ways. First, we will use the interviews to conduct research focused on understanding how people living with HIV are currently being impacted by the pandemic, and we will use this information to inform research design and policy development.

All data use is strictly within the terms of the General Data Protection Regulation [GDPR] which came into effect on 25 May 2018, and its implementing legislation, the Data Protection Act 2018. The study data may be looked at by individuals from Imperial College London, for the purpose of audit and monitoring.

What if something goes wrong?

If you are harmed by taking part in this research project, there are no special compensation arrangements. If you are harmed due to someone's negligence, then you may have grounds for a legal action. Regardless of this, if you wish to complain, or have any concerns about any aspect of the way you have been treated during the course of this study then you should immediately inform the Investigator Professor Helen Ward, email: h.ward@imperial.ac.uk, telephone: +44 (0)20 7594 3303.

If you are still not satisfied with the response, you may contact the Imperial Joint Research Compliance Office.

Who is funding and organising this research?

Imperial College London School of Public Health is funding and leading the research.

Who has reviewed the study?

The Principal Investigator has obtained approval from the Head of Department and Joint Research Compliance Office (JRCO). The day-to-day management of the study will be co-ordinated by Vasiliki (Vas) Papageorgiou.

Contact for Further Information

If you would like more information about the study or have any concerns or questions, you can contact Vas Papageorgiou (email: vasiliki.papageorgiou17@imperial.ac.uk) who will do her best to help.

HOW WILL WE USE INFORMATION ABOUT YOU?

Imperial College London is the sponsor for this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. Imperial College London will keep your personal data for:

- 10 years after the study has finished in relation to data subject consent forms.
- 10 years after the study has completed in relation to primary research data.

We will need to use information from you for this research project.

This information will include your

-Name

- Contact Details, including your email address and telephone number

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.

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.

LEGAL BASIS

As a university we use personally-identifiable information to conduct research to improve health, care and services. As a publicly-funded organisation, we have to ensure that it is in the public interest when we use personally-identifiable information from 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 your data in the ways needed to conduct and analyse the research study.

Health and care research should serve the public interest, which means that we have to demonstrate that our research serves the interests of society as a whole. We do this by following the [UK Policy Framework for Health and Social Care Research](#)

INTERNATIONAL TRANSFERS

There may be a requirement to transfer information to countries outside the European Economic Area (for example, to a research partner). Where this information contains your personal data, Imperial College London will ensure that it is transferred in accordance with data protection legislation. If the data is transferred to a country which is not subject to a European Commission (EC) adequacy decision in respect of its data protection standards, Imperial College London will enter into a data sharing agreement with the recipient organisation that

incorporates EC approved standard contractual clauses that safeguard how your personal data is processed.

SHARING YOUR INFORMATION WITH OTHERS

For the purposes referred to in this privacy notice and relying on the bases for processing as set out above, we will share your personal data with certain third parties.

- Other College employees, agents, contractors and service providers (for example, suppliers of printing and mailing services, email communication services or web services, or suppliers who help us carry out any of the activities described above). Our third party service providers are required to enter into data processing agreements with us. We only permit them to process your personal data for specified purposes and in accordance with our policies.
- The following Research Collaborators / Partners in the study;
 - Positive Voices Study team (HIV Section, Public Health England; Positively UK): we are partnering with them on the larger study interviewing people living with, and affected by, HIV.

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, and normally we will keep information about you that we already have. If a participant decides to leave the study after an interview has taken place, all audio recordings, transcripts and typing of your interview would be destroyed if requested.

If you agree to take part in this study, you will have the option to take part in future research using your data saved from this study.

WHERE CAN YOU FIND OUT MORE ABOUT HOW YOUR INFORMATION IS USED

You can find out more about how we use your information

- by asking one of the research team
- by sending an email to vasiliki.papageorgiou17@imperial.ac.uk

COMPLAINT

If you wish to raise a complaint on how we have handled your personal data, please contact Imperial College London's Data Protection Officer via email at dpo@imperial.ac.uk, via telephone on 020 7594 3502 and/or via post at Imperial College London, Data Protection Officer, Faculty Building Level 4, London SW7 2AZ.

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 ICO

does recommend that you seek to resolve matters with the data controller (us) first before involving the regulator.

Thank you very much for taking the time to consider taking part in this study.

Yours faithfully,

Vas Papageorgiou