



Participant information sheet

Positive Voices is the national survey of the experiences and health care needs of people living with HIV in the UK. You have been invited to take part in the survey to help improve health services and identify the unmet needs of people with HIV.

Your answers are strictly confidential. All information collected is stored securely and your personal details will not be used in any reports.

This study is being carried out by Public Health England (PHE), University College London (UCL) and Imperial College London and is funded by Public Health England and Gilead Sciences Inc. This research has been reviewed and approved by the London Harrow NHS Research Ethics Committee (Project ID 13/LO/0279).

Your participation is voluntary, so take time to decide whether or not you wish to take part.

More information about the survey can be found online at www.ucl.ac.uk/voices.

Thank you.

Positive Voices: the National Survey of People Living with HIV

Why have I been invited?

You have been invited to complete the survey, as you are an adult living with HIV and attended an NHS clinic in the past year. We invite you to share your unique experience and contribute to the improvement of HIV prevention, treatment, and care services.

How do I take part?

You can complete the survey online or on paper. Instructions can be found on the enclosed Questionnaire Booklet. To complete online, you will need a device with internet access and the access code on the front of your questionnaire booklet. To complete on paper, simply complete the enclosed questionnaire and return in clinic or using the FREEPOST envelope. The survey will take about 20 minutes to complete, but it may take less or more time for some people. You can skip any questions you do not want to answer, and you are free to quit the survey at any time.

Why should I take part in the survey?

Positive Voices is the first national, large-scale survey of people living with HIV, which aims to collect data that represents the wider HIV community. The survey asks about a range of issues, such as medical conditions other than HIV, your overall health and quality of life, met and unmet health and social needs, satisfaction with NHS services, education and employment, sex and sexuality, alcohol and drug use, adherence to HIV medication, HIV stigma and discrimination.

These data will provide valuable insights into the issues that most affect the health and lives of people with HIV. The results of the survey will be used to monitor and improve existing HIV services and policies, and to support the provision of new services.

Do I have to take part?

You do not have to take part in the survey. Accepting the survey invitation from the clinic staff does not mean that you have to participate in the survey. Once you leave the clinic, your HIV clinic will have no way of knowing if you choose not to participate. If you choose not to take part, your healthcare and legal rights will not be affected in any way. If you decide to take part, you can quit the survey at anytime.

Will my answers be kept confidential?

Yes. HIV is a sensitive research topic and it is important to ensure that confidentiality is maintained. The information you provide is strictly confidential and only accessed by named members of the research team who have signed a confidentiality agreement (www.ucl.ac.uk/voices/management). Data will be handled in accordance with the Data Protection Act 1998, following strict protocols overseen by the PHE Caldicott Guardian. Your doctors and clinic will not see your answers, and your response will not affect your care in any way.

How will my answers be linked to other data?

The Personal Access Code on the cover of the questionnaire booklet is a code that has been created to link your survey answers to information already collected through PHE's national HIV surveillance system, such as CD4 and viral load results. It is important to link these datasets to understand how lifestyle and experiences can affect your HIV care. The Personal Access Code was linked to your HIV clinic number at the start of the study, and data will be combined by linking the survey answers (which have the Personal Access Code) to the national surveillance records (which have the HIV clinic number). The table that holds the Personal Access Code and HIV clinic number will be kept secure and separate from other data files and only accessed by the two survey coordinators (www.ucl.ac.uk/voices/management). After the CD4 and prescribing data have been combined, the final dataset will be anonymised by irreversibly stripping the Personal Access Code and HIV clinic number. For more information on Public Health England's national HIV surveillance, go to:

<https://www.gov.uk/government/collections/hiv-surveillance-data-and-management>

Data Security

Survey data will be held securely in the HIV/STI Department at Public Health England, with access restricted to members of the study team. Data storage and use is subject to the security and confidentiality requirements governing Public Health England's collection of HIV surveillance data, as per the Data Protection Act 1998 and Section 60 of the Health and Social Care Act. All members of the study team have been trained in handling sensitive data according to Caldicott Guidelines and are required to maintain absolute confidentiality.

Gift Voucher

A £5 High Street Voucher is enclosed as a gift from Public Health England in appreciation for your interest. This is yours to keep whether or not you wish to take part. See the conditions on reverse for where the voucher can be used.

Future research

At the end of the survey, you will be asked to consent for the researchers to link your survey responses to prescribing data at your HIV clinic. You will also be invited to provide contact details to take part in future research. If you do not wish to take part, skip these questions. Your questionnaire is still useful. If provided, your contact details will be unlinked from your answers and stored in a separate, password protected database.

What do I do if I have questions or complaints about the survey?

Please contact the researchers using the details below:

Chris Farey, Survey Administrator HIV/STI Department, Public Health England. London NW95EQ.

Email: positive.voices@phe.gov.uk Phone: 02083277566

If you wish to make a formal complaint you can call patient support services at Camden PCT on 020 3317 3003, or email pss@camdenpct.nhs.uk.