

## The Stigma Survey UK: Participant Information Sheet

### **What is the People Living with HIV Stigma Survey UK?**

The People Living with HIV Stigma Survey UK is a community initiative driven by people with HIV for people with HIV. The survey aims to collect information about the experiences of people living with HIV aged 15+ related to stigma, discrimination. It is funded by MAC AIDS FUND.

East Midlands Sexual Health and Homerton University Hospital NHS Foundation Trust, have come together to deliver the Stigma Survey UK 2019.

You have been invited to take part in the survey to help provide up to date information, which can help to inform policy and improve health services for people with HIV.

Your answers are completely anonymous and confidential. No one looking at the study findings will be able to identify you in any way.

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

<http://www.stigmaindexuk.org>

Thank you

## Why have I been invited?

You have been invited to complete the survey, as you are a person over the age of 15 living with HIV in the UK. We invite you to share your unique experience and contribute to the knowledge around how stigma and discrimination affect the lives of people living with HIV.

## How do I take part?

Simply click on the 'Take the Stigma Survey UK - YP' button on our website's homepage. If you have been invited while attending an HIV clinic you will be able to take the survey in the clinic using one of the study tablet computers, however you can take part using any device with internet access (such as a smart phone or lap top). An email address is provided at the bottom of this sheet if you need to ask any questions. The survey will take about 15 minutes to complete but it may take less or more time for some people. You are not able to log out of the survey and come back later to complete it; **so you need to complete all questions in one session.** The survey may ask some sensitive questions but please try to answer them all.

## Why should I take part in the survey?

The *People Living with HIV Stigma Survey UK 2019* is a large scale survey of people living with HIV in the UK which aims to identify whether people living with HIV experience stigma and discrimination related to HIV and to describe how such stigma affects their daily lives. People living with HIV have contributed to the study design and survey questions and will continue to be involved at all stages of the work.

Data from this study will provide valuable insights into the burden and types of stigma and discrimination directly experienced by people living with HIV in the UK and provide specific information on the situations in which stigma was experienced to inform interventions to reduce stigma for people living with HIV.

## Do I have to take part?

You do not have to take part in the survey. Accepting the survey invitation from staff at your clinic or support organisation does not mean that you have to participate in the survey. Once you leave, they 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 any point. **Your answers will not be saved until you press "Submit" at the end of the survey.**

## **Will my answers be kept confidential and anonymous?**

**Yes** The information you provide is totally confidential. Your answers are anonymous and will not allow you to be identified in any way. Your doctors and clinic will not see your answers, and your response will not affect your care in any way.

## **Data Security and Insurance**

The survey responses reside within an encrypted server with restricted access to members of the study team. Your IP address will not be stored. Working records and other research data will be retained on the secure PHE server for at least 10 years to rebut allegations of scientific fraud.

Homerton University Hospital NHS Foundation Trust holds standard NHS Hospital Indemnity and insurance cover with NHS Litigation Authority for NHS Trusts in England, which apply to this study. This does not affect your legal rights to seek compensation. If you are harmed due to someone's negligence, then you may have grounds for 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. The normal National Health Service complaints mechanisms are also available to you. If you are still not satisfied with the response, you may contact the Imperial AHSC Joint Research Compliance Office.

## **Prize Draw Entry Terms and Conditions**

At the end of the survey, you will be invited to enter a prize draw to win a smart phone. To enter, you must provide an email address or phone number to contact you if you win. Contact details will be stored by PHE and used for the purposes of the prize draw ONLY and will not be linked to your survey response.

Winners will be randomly selected from eligible entries at the end of the survey period. After this date all contact details will be deleted. The number of entries eligible for each draw will be published at [www.stigmaindexuk.org](http://www.stigmaindexuk.org). Multiple entries will be disqualified. Competition winners will be informed by email by December 10th, 2019.

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

For information contact Alastair Hudson (Stigma Index UK Country Coordinator) at [survey@stigmaindexuk.org](mailto:survey@stigmaindexuk.org)

## **What do I do if I feel distressed or upset during or after completing the survey?**

For information and support please contact your healthcare professional in clinic to discuss anything you find upsetting. Alternatively you can contact any of the following organisations:

### **CHIVA**

The Wool Hall, 12 St Thomas Street  
Bristol BS1 6JJ

01179105226 / 07807705062

### **Body and Soul**

St. Ives House, 99-119 Rosebury Ave  
London EC1R 4RE

020 7923 6880

### **Positively UK**

345 City Road  
London  
EC1V 1LR

0207 713 0444

### **HIV I-Base**

107 The Maltings  
169 Tower Bridge Road  
London SE1 3LJ

24 hour helpline: 020 8616 2210

If you have a complaint about the study:

Please email us at [survey@stigmaindexuk.org](mailto:survey@stigmaindexuk.org)

### **Ethical Approval**

This research has been reviewed and approved by the Stanmore REC Committee (Project ID 252729).