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## The Stigma Survey UK – Young People’s Study: Participant Information Sheet

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

The Young 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 young people living with HIV aged 15-24 years related to stigma, discrimination. It is funded by the MAC AIDS FOUNDATION.

The UK’s leading sexual health charity FPA, Imperial College Healthcare NHS Trust, HIV in Young People Network and the Children’s HIV Association have come together to deliver the Stigma Survey UK –YP.

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 young people with HIV. It will give young people living with HIV a voice.

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. More information about the survey can be found online at **[www.stigmamaindexuk.org](http://www.stigmamaindexuk.org)**

Thank you

## Why have I been invited?

You have been invited to complete the survey, as you are a young person between the ages of 15 to 24 years (inclusive) living with HIV. We invite you to share your unique experience and contribute to the knowledge around how stigma and discrimination affect the lives of young people living with HIV.

## How do I take part?

Instructions are on the back of your survey invitation card. 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 and on the study invitation card if you need to ask any questions. The survey will take 15 to 25 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 asks some sensitive questions. You can skip any questions you do not want to answer.

## Why should I take part in the survey?

The *Young People Living with HIV StigmaSurveyUK 2016* is a large scale survey of people living with HIV in the UK which aims to identify whether young 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 young 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 young people living with HIV. It will give young people living

with HIV a voice.

### **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 and handled in accordance with the Data Protection Act 1998. 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. When you complete the survey, the final page will give instructions on how to clear your browser history. 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.

Imperial College Healthcare NHS 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 one of ten iPhones. To enter, you must provide an email address or phone number to contact you if you win. Contact details will be used for 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 no later than May 1<sup>st</sup> 2017.

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

For information contact Alastair Hudson (Stigma Index UK Country Coordinator) Email: [stigmasurvey@fpa.org.uk](mailto:stigmasurvey@fpa.org.uk)

### **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 CHIVA, Positively UK or Body and Soul.

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**CHIVA**

The Wool Hall, 12 St Thomas Street  
Bristol BS1 6JJ  
Telephone: 01179105226 / 07807705062

**Body and Soul**

St. Ives House, 99-119 Rosebury Ave  
London EC1R 4RE  
Telephone: 02079236880

If you have a complaint about the study:

Please email us at [stigmasurvey@fpa.org.uk](mailto:stigmasurvey@fpa.org.uk)

**Ethical Approval**

This research has been reviewed and approved by the Camden and King's Cross REC Committee (Project ID 210818).