



The UK People Living with HIV Stigma Index 2015: Participant information sheet

What is the UK People Living with HIV Stigma Index?

The People Living with HIV Stigma Index is a community initiative driven by people with HIV for people with HIV. The UK People Living with HIV Stigma Index 2015 survey aims to collect information about the experiences of people living with HIV related to stigma, discrimination and their rights and is funded by MAC AIDS.

The UK's leading sexual health charity FPA and Public Health England (PHE) have come together in collaboration to deliver the *People Living with HIV Stigma Index*; UK Stigma Index 2015.

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 strictly 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

Thank you

Why have I been invited?

You have been invited to complete the survey, as you are an adult (over 18 years) living with HIV in the United Kingdom. We invite you to share your unique experience and contribute to the knowledge around how stigma and discrimination affects the lives of people living with HIV in the UK.

How do I take part?

Instructions are on the back of your survey invitation card. If you have been invited while attending an NHS 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). A study volunteer may be available in the clinic if you need to ask questions and an email address is provided at the bottom of this sheet and on the study invitation card. The survey will take 20 to 40 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; you should 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 UK People Living with HIV Stigma Index 2015 is a large scale survey of people living with HIV in the UK which aims to identify whether people living with HIV in the UK 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 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 the clinic staff or study volunteer 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 any point. Your responses 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

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.

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 twenty iPads. To enter, you must provide an email address for us 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. Multiple entries will be disqualified. Competition winners will be informed by email no later than May 1st 2015.

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

For information contact Alastair Hudson (Stigma Index UK Country Coordinator)

Email: StigmaIndex@phe.gov.uk

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

For information and support:

Terence Higgins Trust - the largest HIV charity in the UK offering a wide range of HIV information and support services run a helpline for those affected by HIV

THT Direct: 0808 802 1221 Monday-Friday 10am-8pm. This number is free to call from all UK landlines and most UK mobiles and will not appear on your telephone bill.

www.tht.org.uk

For confidential emotional support 24 hours a day:

Samaritans

www.samaritans.org.uk

Support by phone: 08457909090

Support by email: jo@samaritans.org

If you have a complaint about the study:

Please email us at StigmaIndex@phe.gov.uk

Ethical Approval

This research has been reviewed and approved by the Brighton and Sussex NHS Research Ethics Committee (Project ID 14/LO/1983)