



Protecting and improving the nation's health

## The Stigma Survey UK – BAME Healthcare Study: Participant Information Sheet

### **Why have I been invited?**

You have been invited to complete the survey because you are an adult member of a BAME group living with HIV in the UK. We invite you to share your unique experiences and contribute to the knowledge around your rights and how stigma and discrimination affect the lives of BAME people living with HIV within the healthcare setting.

### **How do I take part?**

You can complete this survey by going to the homepage of our website. 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.**

### **Why should I take part in the survey?**

The Stigma Survey UK – BAME in Healthcare is a large scale survey of people living with HIV in the UK which aims to identify the extent to which members of BAME communities who are living with HIV experience stigma and discrimination in the healthcare setting and how this impacts their medical care. 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 BAME populations living with HIV in the UK and provide specific information on the situations in which stigma was experienced within healthcare setting. This will help to inform interventions to reduce stigma and improve the patient experience.

### **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.

**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.

If you have a complaint about the study:

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