

# Positive Voices: National Survey of People with HIV

<b>Submission date</b> 11/10/2013	<b>Recruitment status</b> No longer recruiting	<input type="checkbox"/> Prospectively registered <input type="checkbox"/> Protocol
<b>Registration date</b> 11/10/2013	<b>Overall study status</b> Completed	<input type="checkbox"/> Statistical analysis plan <input type="checkbox"/> Results
<b>Last Edited</b> 16/03/2017	<b>Condition category</b> Infections and Infestations	<input type="checkbox"/> Individual participant data <input type="checkbox"/> Record updated in last year

## Plain English summary of protocol

### Background and study aims

The number of people living with human immunodeficiency virus (HIV) [PLHIV] in the UK is estimated at 100,000 in 2012, due to effective HIV treatment and ongoing new HIV diagnoses. There is a need to better understand the patterns of risk behaviour in PLHIV, the prevalence of HIV-associated co-morbidities, and attitudes and satisfaction with current models of care, in order to plan HIV prevention, treatment and care services.

### Who can participate?

HIV+ individuals aged 18+ attending NHS HIV specialist services will be eligible to take part.

### What does the study involve?

The project will utilise the national census of HIV positive individuals in care [SOPHID] as a national sampling frame to invite a random sample of PLHIV to complete an online questionnaire. Topics covered will include: sexual and drug taking behaviours; co-morbidities and risk behaviours associated with chronic disease; use of health services; quality of life; satisfaction with care; and attitudes and experiences toward living with HIV.

The project will be carried out in two phases. In Phase 1, we will use mainly qualitative methods with patients, clinic staff, and other key informants to develop and validate the survey tool and explore the acceptability and feasibility of a variety of incentives targeting clinics and patients to improve survey response rates. In Phase 2, the survey will be conducted in twenty clinics. In the initial small study, two interventions will be studied (incentive and recruitment method).

Incentive method: Patients will be randomly allocated to one of four incentives:

1. Control - no incentive
2. Offer of health information
3. A prize draw for gift vouchers
4. Offer of health information plus a prize draw for gift vouchers

Recruitment method, Clinic level randomisation - clinics will be randomised to recruit either : a) a pre-defined randomly selected list of patients sent from Health Protection Agency OR b) all patients attending clinic during a specified time period.

### What are the possible benefits and risks of participating?

There are no direct benefits for patients who participate, unless the patient is randomly

allocated to receive health information or entry into a prize draw. The indirect benefits are contributing to the evaluation and improvement of their HIV services. The risks of participating are minimal, but the survey includes questions of a sensitive nature and therefore patients may feel some distress or discomfort. Patients are free to quit the survey at any time, and details of local HIV support organisations will be provided.

Where is the study run from?

The study is run from Public Health England in London.

When is the study starting and how long is it expected to run for?

The qualitative work of Phase 1 will recruit from July - October 2013. Phase 2 (the initial small study) will start recruitment in November 2013 until October 2014.

Who is funding the study?

National Institute for Health Research (UK).

Who is the main contact?

Meaghan Kall, Survey Coordinator

meaghan.kall@phe.gov.uk

## Contact information

### Type(s)

Scientific

### Contact name

Miss Meaghan Kall

### Contact details

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## Additional identifiers

### Protocol serial number

14460

## Study information

### Scientific Title

Development and Implementation of Positive Voices: the National Survey of People Living with HIV

### Acronym

## Positive Voices

### Study objectives

The main objectives of the study are to:

1. Evaluate the method of delivering the survey with the highest response rate
2. Identify differences between survey respondents and non-respondents

Protocol can be found at: <http://www.ucl.ac.uk/silva/voices/pdfs/protocol>

On 06/06/2014 the anticipated end date was changed from 01/04/2014 to 31/10/2014.

### Ethics approval required

Old ethics approval format

### Ethics approval(s)

London Harrow Research Ethics Committee, 28/03/2013, ref: 13/LO/0279

### Study design

Observational and interventional two tiered factorial randomised controlled trial; Design type: Qualitative

### Primary study design

Interventional

### Study type(s)

Quality of life

### Health condition(s) or problem(s) studied

Topic: Infection; Subtopic: Infection (all Subtopics); Disease: Infectious diseases and microbiology

### Interventions

Incentive, Patients will be randomised to one of four incentive packages in a factorial design:

1. Control - no incentive
2. Offer of health information
3. A prize draw for gift vouchers, or
4. Offer of health information plus a prize draw for gift vouchers

Recruitment method, Clinic level randomisation - clinics will be randomised to recruit either : a) a pre-defined randomly selected list of patients sent from Health Protection Agency OR b) all patients attending clinic during a specified time period

The total duration of intervention varies by clinic recruitment method. Clinics assigned to recruit from a pre-selected list of patients will run the study for 4 months. Clinics assigned to recruit sequential attendees, will run the study for 2 months. There will be no follow up with patients after this time.

### Intervention Type

Other

### Phase

Not Applicable

**Primary outcome(s)**

Response rates; Timepoints: Which method of incentivising clinics and participants achieves the highest response rate.

Assessed at the end of the study. For example, response rates will be calculated by counting the total number of survey responses, the total number of survey invitation slips returned by the clinics, and retrospectively counting the actual number of HIV+ patients who attended during the study period.

**Key secondary outcome(s)**

1. Assess whether response rates among the various risk groups and age groups are representative of the national HIV population (+/-10%).
2. Assess key determinants of variation in response rates by risk group, age group, geography, and clinic size.

Assessed at the end of the study.

**Completion date**

31/10/2014

**Eligibility****Key inclusion criteria**

Phase 1: Focus Group Discussion & Cognitive Interviews:

1. HIV positive
2. Male and female, aged 18 and over
3. Accessing care at an NHS HIV clinic

Phases 2 & 3: Pilot and Full Survey:

1. HIV positive
2. Male and female, aged 18 and over
3. Accessing care at an NHS HIV clinic
4. Reported to SOPHID in the previous calendar year

**Participant type(s)**

Patient

**Healthy volunteers allowed**

No

**Age group**

Adult

**Lower age limit**

18 years

**Sex**

All

**Key exclusion criteria**

## **Phase 1: Focus Group Discussion & Cognitive Interviews:**

1. Unable to speak English
2. Participant declines audio recording of the discussion (for focus group discussions only)

## **Phases 2 & 3: Pilot and Full Survey:**

Unable to complete online questionnaire due to language or literacy

### **Date of first enrolment**

25/07/2013

### **Date of final enrolment**

31/10/2014

## **Locations**

### **Countries of recruitment**

United Kingdom

England

### **Study participating centre**

**Centre for Infections**

London

United Kingdom

NW9 5EQ

## **Sponsor information**

### **Organisation**

Public Health England (UK)

## **Funder(s)**

### **Funder type**

Government

### **Funder Name**

NIHR (UK) - Public Health Research; Grant Codes: CHPR-2011-006

## **Results and Publications**

## Individual participant data (IPD) sharing plan

### IPD sharing plan summary

Not provided at time of registration

### Study outputs

Output type	Details	Date created	Date added	Peer reviewed?	Patient-facing?
<a href="#">HRA research summary</a>			28/06/2023	No	No
<a href="#">Participant information sheet</a>	Participant information sheet	11/11/2025	11/11/2025	No	Yes
<a href="#">Study website</a>	Study website	11/11/2025	11/11/2025	No	Yes