

BACKGROUND

- Patient-reported outcome and experience data are increasingly needed to understand the determinants of poor health outcomes and tailor service provision
- Routine collection of this data poses a unique challenge to those responsible for HIV surveillance and monitoring.
- We present the methods of a new national cross-sectional probability survey of people accessing HIV care designed to be integrated as part of routine national HIV surveillance in the United Kingdom

DESCRIPTION

Formative Research Phase (2013-2015)

- STAKEHOLDER INVOLVEMENT** The method and questionnaire were developed with an Advisory Group of patient representatives, clinicians, academics, commissioners and civil society.
- SURVEY DESIGN** An omnibus-style survey was designed using validated survey questions and instruments to allow comparisons and tested through cognitive interviews with people with HIV (Table 1)
- METHOD DEVELOPMENT** Qualitative interviews with HIV patients and clinic staff identified the most feasible, acceptable, and sustainable methods to implement the survey and recruit participants.
- PILOTING AND EVALUATION** In 2014 the survey was piloted in 30 HIV clinics. Survey metadata were collected (e.g. reasons for non-recruitment, implementation issues flagged by clinics) to inform methods for the national survey

Topic	Questions
HIV diagnosis and treatment	HIV diagnosis facility, ART adherence (ACTG-14 day), side effects
Comorbidities	Ever diagnosed health conditions & co-infections, year/age of diagnosis and non-ART medication
Health and Well-being	Life satisfaction (ONS), health status (SF-36), quality of life (EQ-5D-5L), generalised psychiatric disorders (GHQ-12)
Stigma & Discrimination	Disclosure, discrimination in healthcare settings
Sex & Relationships	Sexual history (main and casual partners), STI diagnoses, women's sexual and reproductive health
Lifestyle	BMI, smoking, alcohol and drug use, injecting history
Service Use & Satisfaction	GP and HIV service use and satisfaction, patient experience measures, use of HIV support services
Sociodemographic	Employment and income, education, housing, religion, sexual orientation
Met and Unmet Needs	Need for and receipt of HIV related services, health services, social and welfare services in past year

LESSONS LEARNED

- **Full costing from 2013-2018 was £648,000:** £212,000 for the formative research phase and £436,000 for the national survey. This includes staff (1 FTE coordinator, 2 FTE junior scientist and 1 FTE administrator) and non-staff costs (e.g. printing, postage, incentives)
- After initial investment for development, the annual cost to run (on 3 yearly cycle) was £145,000/year, or **£98.60 per survey** representing **excellent value for money** for a national probability survey.
- **Low denomination, unconditional monetary vouchers were effective** to boost response rates, particularly in traditionally underrepresented groups
- **Choice of online or paper response** formats in response to patient feedback ensured inclusivity
- NHS research approvals were vital to give **access to the local flexible workforce** for recruitment, particularly useful for large HIV clinics
- **Email and postal recruitment options** ensured infrequent attendees (stable patients on annual appointments, rural residents) were included

National Survey Implementation (2016-2018)

1 SAMPLING

- National HIV surveillance dataset was used as a sampling frame
- A two-stage sampling design was used:
 1. All HIV clinics in England and Wales reporting ≥5 patients in 2015 were invited to take part (Figure 1)
 2. A random sample of patients was drawn from the 2015 attendance list of participating clinics (based on clinic size)

2 RECRUITMENT

- Patients were approached by local hospital staff in person, by post or by email
- Surveys were self-completed on paper or online (Figure 2). Paper surveys could be returned in clinic or via a Freepost envelope included in the survey pack
- An unconditional £5 high street voucher was included as an incentive
- Research ethics and HRA approval was obtained

3 RESPONSE

- Recruitment ran from January – September 2017
- 12,114 patients were randomly sampled (~20% of patients at each clinic)
- 8,608 (71%) patients were successfully contacted
- **4,422 patients completed the survey → 51% response rate**
- 87% completed on paper and 13% online
- Respondent characteristics were closely representative of the national cohort on key variables (±5%) (Figure 3)

CONCLUSIONS / NEXT STEPS

- With relatively modest investment, robust formative research methods, and collaboration with multiple stakeholders including people with HIV and recruiting staff, a good response rate is achievable for clinic-based recruitment of people with HIV
- Probability sampling, using national surveillance records as a sampling frame, successfully produces generalisable national estimates of key patient-reported outcome data
- Weighting on a range of respondent characteristics will further improve representation and generalisability
- Securing long-term funding continues to present a challenge, but with a first round of data collection complete several potential funding sources have expressed interest.
- The optimal interval to repeat the survey is yet to be determined and statistical tests using the pilot and national data will be done to inform this decision

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Positive Voices advisory group members: Dr Richard Gilson (UCL), Dr Anthony Nardone (PHE), Dr Maryam Shahmanesh (UCL), Dr Cath Mercer (UCL), Prof Helen Ward (Imperial College), Prof Graham Hart (UCL), Prof Jane Anderson (PHE), Yusef Azad (NAT), Prof Jonathan Elford (City University), Dr Ann Sullivan (C&W), Dr Alan McOwan (C&W), Prof Jackie Cassell (Brighton & Sussex Medical School), Julie Musonda (UK-CAB), Jane Bruton (Imperial), Meaghan Kall (PHE) and Valerie Delpech (PHE)



73 of 184 (40%) of eligible clinics agreed to take part

Figure 1: Location of 73 participating HIV clinics

In focus groups, participants said they would be more likely to respond if they received feedback on the survey results, so a survey website was created for information, news and to access the online questionnaire

Paper or online survey options were offered based on results of focus groups with people with HIV which found people preferred either online or paper but rarely liked both



Figure 2: a) promotional poster, b) paper questionnaire and c) online questionnaire

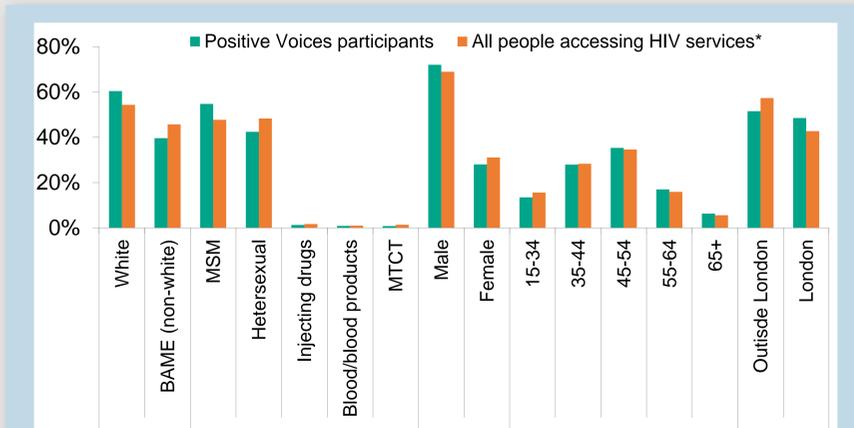


Figure 3: Characteristics of Positive Voices survey respondents compared to all people accessing HIV services
* HARS clinic attendees known to be alive to end 2016, aged >18 and resident in England or Wales