Development of Positive Voices: the national survey of people living with HIV

Meaghan Kall1, Maryam Shahmanesh2, Anthony Nardone1, Richard Gilson2, Valerie Delpech1

1 HIV/STI Department, Public Health England, London, UK
2 Centre for Sexual Health and HIV Research, University College London, UK

INTRODUCTION

Positive Voices is a new national HIV patient survey developed by Public Health England in partnership with University College London, which aims to better understand the experiences and healthcare needs of people living with HIV.

The survey was developed under the guidance of an Advisory Group including patient representatives, clinicians, academics, commissioners and civil society. The survey will be administered via HIV clinics, and will involve a random sample of patients attending for HIV care to complete a questionnaire.

The questionnaire includes questions on socio-demographics, HIV treatment, co-morbidities, quality of life, sexual behaviour, alcohol tobacco and drug use, service use and satisfaction, and experiences with stigma and discrimination.

We report on Phase 1 of the project involving formative work using qualitative methods with patients and HIV clinic staff to explore the acceptability and feasibility of the survey tool, and its proposed delivery as a self-completed web-based survey.

METHODS

The qualitative methods (Jun 2013-Jun 2014) consisted of:

(i) semi-structured interviews with clinic staff conducted on-site at 23 HIV clinics to assess the feasibility of delivering the survey

(ii) three HIV patient focus groups (including 6-8 participants) to assess the acceptability of the survey, and to identify barriers and incentives to completion

(iii) cognitive interviews with patients to develop the questionnaire (n=7).

RESULTS

Overall, clinic staff were enthusiastic about the survey and keen for patients to be involved.

Staff views, concerns and suggestions on how to improve the survey are summarised in Figure 1.

In focus groups, patients felt the survey was an opportunity to “have a say” in improving HIV services. There were mixed views on the feasibility of a web-based survey and the usefulness of incentives to encourage survey completion (Figure 2).

RESULTS (cont.)

- Cognitive interviewing with patients (n=7) did not highlight any major problems with the questionnaire.
- Respondents’ reports related to the visual layout and question flow, clarification of wording, and improving answer options.
- A small number of questions reported as potentially intrusive or conceptually difficult were eliminated.

CONCLUSIONS

- As a result of the formative work, two recruitment methods were selected to be tested by clinics in a cluster-randomised pilot study.
- A prize draw of high street vouchers will be tested as an incentive in a second randomisation.
- Information sheet updated to make confidentiality and anonymity statements more prominent.
- A Freephone telephone option will be made available to increase accessibility of the survey.
- The questionnaire development phase was extended, with more emphasis on wording and flow. The layout of the questionnaire is being improved, and survey software upgraded to include features which streamline and optimise the survey for mobiles.

FUTURE PLANS - PILOT

- “Positive Voices” will be piloted in 29 HIV clinics across England and Wales between May and September 2014 (Figure 3).
- The study aims to approach 4,500 patients, or 20% of the total clinic attendees, and reach a 50% response rate.
- The pilot will:
  1. Measure the effect of different recruitment method and incentives on response rate.
  2. Evaluate representativeness of the respondent sample.
  3. Assess feasibility of delivering the survey in the clinic setting
  4. Compare respondents and non-respondents
  5. Assess data quality, including variable completion and linkage rates to SOPHID records.

ACKNOWLEDGEMENTS

We thank the people who helped organise the focus groups: (Charlie Hughes, Royal Hallamshire Hospital, Sheffield; Maraven Nkawana, RHPN & Ted Taiwo, THF Bristol; and Chris Sandford, Mortimer Market Centre, London) and cognitive interviews (Chris Sandford, Mortimer Market Centre, London).

We also thank the staff at our pilot clinics who participated in the staff interviews, and the members of the Advisory Group (Prof Graham Hart, Prof Jane Anderson, Dr. Ann Sullivan, Dr. Cath Mercer, Yusef Azad, Jess Peck, Prof Jackie Cassell, Julie Musonda, Dr. Amin McOwen, Jane Bruton, Michelle Croston, Prof Jonathan Effer, Lamy Gunney, and Prof Helen Ward).