Development of a nationally representative HIV patient survey: Experiences from the Positive Voices survey in the United Kingdom

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BACKGROUND

- Full costing from 2013-2016 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 year cycle) was £140,000/year or £96.60 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 ignorant (affordable) (stable patients on annual appointments, rural residents) were included

LESSONS LEARNED

- 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 plot and national data will be done to inform this decision

CONCLUSIONS / NEXT STEPS

- Many thanks to all of the Positive Voices survey participants & staff at 73 recruiting HIV clinics

Positive Voices advisory group members: Dr Richard Gilson (UCL), Dr Anthony Nardone (PHE), Dr Maryam Shahmanesh (UCL), Dr Kath Mercuri (UCL), Prof Helen Ward (Imperial College), Prof Graham Hart (UCL), Prof Jane Anderson (PHE), Yusef Elford (Brighton & Sussex Medical School), Prof Jackie Capsei (Brighton & Sussex Medical School), Dr Alan McCowan (CAB), Prof Jane Anderson (PHE), Prof Jackie Capsei (Brighton & Sussex Medical School), Prof Jackie Capsei (Brighton & Sussex Medical School), Prof Jackie Capsei (Brighton & Sussex Medical School)

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