Title: Patient experience within NHS HIV specialist services: results from the Positive Voices pilot survey

Abstract: Background: Ensuring that people have a good experience with their care is an important health outcome, and should be measured to drive improvements in the quality of care. The Positive Voices survey, piloted in May – Nov 2014, was the first effort to collect patient-reported experience measures (PREMs) in a representative sample of HIV patients accessing HIV specialist services. We present the results of the HIV patient satisfaction and experience questions. Methods: Positive Voices is a web-based, self-completed, cross-sectional questionnaire survey completed by patients attending 30 HIV specialist outpatient services in England and Wales. Participants were asked to rate their HIV clinic out of 100, and agree or disagree with three generic (i.e. non-condition specific) PREM statements: 1) I have enough information about my HIV, 2) I feel supported to self-manage my HIV, 3) I am involved in decisions about my HIV care. A fourth HIV-specific PREM was included; 4) I feel that my HIV specialist and my GP communicate well regarding my health (for those registered and disclosed to GP). Agreement was defined as a “Strongly Agree” or “Agree” response. Results: 779 patients completed the survey. Mean HIV clinic rating was 91.7% (median 96% (IQR 90-100)). No difference in rating was observed by ethnicity (mean rating: white=91.3%, black=92.5%, other=93.8%), gender (female=93.3%, male 91.3%), and age (92.9% age<35, 92.1% age35-44, 90.5% age 45-54, 92.0% age>55). Inter-clinic variation (ICV) ranged from 84.7%-96.1%. The proportion agreeing with the three generic PREM questions was: 1) 98.2% (89.7%-100% ICV, 2) 97.3% (80%-100% ICV) and 3) 95.8% (80%-100% ICV). For the 3 generic PREMs, the proportion agreeing remained>95% for all sex, ethnicity, and age groups, except for PREM 3); which was 94% for respondents of black ethnicity and 93.9% for those aged 35-44. Agreement with the HIV-specific PREM 4) was 81.4% overall: lower for black patients 76.4% compared to white 82%, and other ethnicities (87.5%). There was no variation by sex or age. Inter-clinic mean agreement ranged from 60% - 100%. Conclusion: The quality of patient experience with HIV specialist services is very high overall, with little variation by clinics or patient characteristics indicating high equity of care across age, sex, and ethnicity groups. The use of PREMs is an opportunity to involve HIV patients in the process of service evaluation and support the continued improvement of HIV care.