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

Meaghan Kall, Valerie Delpech, Richard Gilson, Maryam Shahmanesh, Anthony Nardone for the Positive Voices Study Group
Acknowledgements

Thanks to all the Positive Voices survey participants

Positive Voices Study Group

Advisory Group: Prof Graham Hart (UCL), Prof Jane Anderson (PHE), Yusef Azad (NAT), Prof Jonathan Elford (City University), Prof Helen Ward (Imperial College), Dr Ann Sullivan (C&W), Dr Cath Mercer (UCL), Dr Alan McOwan (C&W), Jess Peck (NHS England), Prof Jackie Cassell (Brighton and Sussex Medical School), Julie Musonda (UK-CAB), Jane Bruton (NHIVNA)

Clinic teams

- Kobler Clinic - Chelsea & Westminster Hospital
- Mortimer Market Centre, UCLH, London
- St. Mary's Hospital, London
- St. George's Hospital, London
- Homerton University Hospital, London
- Leicester Royal Infirmary, Leicester
- Royal Hallamshire Hospital, Sheffield
- Cardiff Royal Infirmary, Cardiff
- Addenbrooke's Hospital, Cambridge
- Gloucester Royal Hospital, Gloucester
- York Teaching Hospital, York
- Royal Victoria Infirmary, Newcastle upon Tyne
- Kingston Hospital, Kingston
- Royal Gwent Hospital, Newport
- Ipswich Hospital
- Queen Elizabeth Hospital, Birmingham
- North Manchester General Hospital
- Heartlands Hospitals, Birmingham
- Derriford Hospital, Plymouth
- Great Western Hospital, Swindon
- Southmead Hospital, Bristol
- The James Cook University Hospital, Middlesbrough
- Royal Bournemouth General Hospital
- Weymouth Community Hospital, Weymouth
- Manor Hospital, Walsall
- Southend University Hospital
- Norfolk & Norwich University Hospitals
- Russells Hall Hospital, Dudley
- Royal Berkshire Hospital, Reading
- Watford General Hospital, Watford
• 81,510 people in HIV care, rising annually. Quality of HIV clinical care is high

• NHS drive to monitor and improve quality of health service

• NHS Outcomes Framework set out patient experience as a key health outcome

• From April 2013, health services obligated to collect national-level patient experience data in HIV services

The five domains for measuring quality of care: NHS Outcomes Framework

- **Domain 1**: Preventing people from dying prematurely;
- **Domain 2**: Enhancing quality of life for people with long-term conditions;
- **Domain 3**: Helping people to recover from episodes of ill health or following injury;
- **Domain 4**: Ensuring that people have a positive experience of care; and
- **Domain 5**: Treating and caring for people in a safe environment; and protecting them from avoidable harm.
Methods: Positive Voices survey

• May – November 2014

• Adults randomly selected from 30 HIV clinics - inside/outside London, large/small clinics

• Self-completed, web-based, cross-sectional survey

• Behavioural and healthcare needs: healthcare usage and satisfaction; sexual behaviour, alcohol, tobacco, drug use; co-morbidities; stigma; quality of life; socio-demographics

• 781 responses

• 22.5% response rate
1. Present pilot survey results on patient satisfaction from a national probability survey of people living with HIV

2. Describe factors impacting patient experience with health care services
Patient Experience questions

1. Health Service rating scales (ranking 0-100)
   - HIV specialist services
   - General practitioner

2. Patient Reported Experience Measures (PREMs)
   - Likert scale on agreement
   - Many generic PREMs for long-term conditions, no validated HIV specific PREMs
     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”
     4. “I feel that my HIV specialist and my GP communicate well regarding my health”
Participant characteristics

Positive Voices n=782, med age 47 [IQR 40-54]
SOPHID (18+ E&W) n=71303, med age 43 [IQR 40-54]

Standardisation (SOPHID)
• Level 1 – sampling weights by clinic
• Level 2 – post-stratification by age, ethnicity, sex and risk group

On ART

MSM Female Hetero Male White Black African On ART

- SOPHID
- Positive Voices
“Overall, how would you rate your HIV specialist services?”

N=730
Mean 91.4
Median 96 (IQR 90,100)
“Overall, how would you rate your general practitioner (GP)?”

N=686
Mean 68.6
Median 79.5 (IQR 50, 91)

p<0.05
**Results: GP rating by last GP visit**

“*Overall, how would you rate your general practitioner (GP)?*”

<table>
<thead>
<tr>
<th>Last GP Visit</th>
<th>GP Rating</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Past month</td>
<td>72.2</td>
<td>300</td>
</tr>
<tr>
<td>Past year</td>
<td>66.8</td>
<td>274</td>
</tr>
<tr>
<td>&gt;1 year ago</td>
<td>62.0</td>
<td>96</td>
</tr>
<tr>
<td>Never</td>
<td>25.4</td>
<td>2</td>
</tr>
<tr>
<td>Don't remember</td>
<td>75.5</td>
<td>13</td>
</tr>
</tbody>
</table>

Unit of measurement: %
HIV services vs GP rating

Table:

<table>
<thead>
<tr>
<th>HIV services rating</th>
<th>GP rating</th>
</tr>
</thead>
<tbody>
<tr>
<td>90-100</td>
<td>76.4%</td>
</tr>
<tr>
<td>90-100</td>
<td>33.7%</td>
</tr>
<tr>
<td>80-89</td>
<td>13.3%</td>
</tr>
<tr>
<td>80-89</td>
<td>16.3%</td>
</tr>
<tr>
<td>70-79</td>
<td>6.2%</td>
</tr>
<tr>
<td>70-79</td>
<td>13.3%</td>
</tr>
<tr>
<td>60-69</td>
<td>1.8%</td>
</tr>
<tr>
<td>60-69</td>
<td>7.7%</td>
</tr>
<tr>
<td>50-59</td>
<td>0.7%</td>
</tr>
<tr>
<td>50-59</td>
<td>8.2%</td>
</tr>
<tr>
<td>&lt;50</td>
<td>1.6%</td>
</tr>
<tr>
<td>&lt;50</td>
<td>20.9%</td>
</tr>
</tbody>
</table>

Pie chart:
- Same rating: 21.2%
- HIV rated higher: 72.2%
- GP rated higher: 6.6%
Results: patient-reported experience measures (PREMs)

"I have enough information about my HIV" 98% agreement

- Strongly disagree: 1%
- Disagree: 37%
- Agree: 61%
- Strongly agree: 1%

"I feel supported to self-manage my HIV" 95% agreement

- Strongly disagree: 2%
- Disagree: 38%
- Agree: 57%
- Strongly agree: 2%

"I am involved in decisions about my HIV care" 91% agreement

- Strongly disagree: 4%
- Disagree: 37%
- Agree: 54%
- Strongly agree: 4%

"I feel that my HIV specialist and my GP communicate well regarding my health" 72% agreement

- Strongly disagree: 7%
- Disagree: 8%
- Agree: 34%
- Strongly agree: 38%
- Don't know: 13%
“I feel that my HIV specialist and my GP communicate well regarding my health”
Limitations

• Low response rate ➔ Non-response bias

• Limited service-side data (appointment availability, waiting times, staffing levels)

• Lack of validated HIV-specific PREMS
Conclusions

• Quality of HIV clinical care is high in the UK. The Positive Voices pilot survey is an effective way to collect patient-experience data, provides neutrality, standardised and comparable data

• People living with HIV rate their HIV specialist service highly, with little variation by patient characteristics. They report having information about HIV, being supported to self-manage, and being involved in decisions about their care.

• Further work is needed to better understand and improve GP rating, including communication between HIV specialist services

• Provides important baseline data of patient experience and could be part of the HIV Quality Dashboard if implemented nationally

• Patient experience surveys provide an opportunity to involve patients in service evaluation