Positive Voices: Experiences & Unmet Needs of people with HIV in England & Wales

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Methods

- February – September 2017
- Nationally representative
  - Random sample from national surveillance dataset
  - ~1 in 5 patients/clinic
- Clinic-based recruitment
  - Face to face, post or email
- Self-completion
  - Paper (87%) or Online (13%)
- Incentive £5 shop voucher
73 clinics
51% response rate
4,422 responses
1 in 20 people with HIV

2,451 – London  56 – Liverpool
150 – Manchester  218 – Brighton
## Demographic Profile

**Positive Voices Participants**

- **White**
- **BAME (non-white)**
- **MSM**
- **Heterosexual**
- **Injecting drugs**
- **Blood/blood products**
- **MTCT**
- **Male**
- **Female**
- **15-34**
- **35-44**
- **45-54**
- **55-64**
- **65+**
- **Outside London**
- **London**

**All people accessing HIV services**

*2016 HIV clinic attendees, aged ≥18 resident England and Wales*
Satisfaction with HIV clinic: 2017

- Clinic provides enough information about my HIV
- I feel supported to self-manage my HIV
- I am involved in decisions about treatment & care
- Have enough time to discuss everything at appointments
- Staff listen carefully to what I have to say

Legend:
- Male
- Female
- <35 years
- 35-44 years
- 45-54 years
- 55+ years
- White
- Black
- Other
Quality of life: utility score (EuroQol)

- General UK Population: 0.86
- Positive Voices: 0.83

Factors affecting utility score:
- Gender: Men > Women > Trans/Non-binary
- Treatment: On ARV > Not on ARV
- Exposure group: Sex between Men > Injecting Drugs > Heterosexual sex > Blood/blood products > Mother to child
- Ethnicity: White > Black African > Other White > Other BAME
- Age Group: 18-34 > 35-44 > 45-54 > 55-64 > 65+
People with HIV vs. general population reporting problems:

- Mobility: 27% (HIV) vs. 26% (general public)
- Self-care: 13% (HIV) vs. 9% (general public)
- Usual Activities: 28% (HIV) vs. 24% (general public)
- Pain and Discomfort: 46% (HIV) vs. 42% (general public)
- Anxiety/Depression: 50% (HIV) vs. 24% (general public)

People with HIV: Red bars; General public: Blue bars.
Met and unmet needs

Three sections

• HIV-related services (6)
• Health-related services (11)
• Social & Welfare services (12)
Defining “Need”: those who needed this help in the past year

<table>
<thead>
<tr>
<th>In the last YEAR...</th>
<th>I have received this help.</th>
<th>I needed this help, but could not get it.</th>
<th>I needed this help, but did not ask or look for it.</th>
<th>I did not need this help.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Information about living with HIV (including websites)</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
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<tr>
<td>HIV treatment advice</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
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<tr>
<td>Professional help to take your HIV tablets on time or correctly</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Peer support/social contact with other people with HIV</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
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<tr>
<td>Help disclosing your HIV status</td>
<td>☐</td>
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<td>☐</td>
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<tr>
<td>Long term condition management support</td>
<td>☐</td>
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</table>
Defining “Unmet need”:
those who did not receive this help in the past year, of those who needed it
What help do you need?

- HIV-RELATED NEEDS: 83%, 20%
- HEALTH-RELATED NEEDS: 77%, 47%
- SOCIAL AND WELFARE NEEDS: 45%, 62%
Met and Unmet Needs:
HIV treatment advice and information

**HIV treatment advice**

- Need: 61%
- Met: 93%
- Not Needed: 39%

**Information about living with HIV (including websites)**

- Need: 47%
- Met: 87%
- Not Needed: 53%

**Average HIV Clinic Rating:**

- 9.3

- **98%** Enough information
- **94%** Involved in decisions
- **95%** Supported to self-manage
- **96%** Enough time at appts
- **97%** Staff listen
Met and Unmet Needs: Peer support

Peer support/social contact with other people living with HIV

Not needed 68%
Need 32%
Met 57%
Unmet 43%

28,000 needed peer support
12,000 with unmet need
Met and Unmet Needs: Drug treatment and Chemsex Support

Drug detox or maintenance treatment
- Not Needed: 95%
  - Need: 5%
  - Met: 40%
  - Unmet: 60%

Chemsex support
- Not Needed: 94%
  - Need: 6%
  - Met: 45%
  - Unmet: 55%

Gay and bisexual men reported chemsex in past 3 months: 15%
Any drugs in past 3 months:
- Cannabis: 27%
- Cocaine: 9%
- Mephedrone: 0%
- Ecstasy: 5%
- Crack: 5%
Met and Unmet Needs: Help dealing with loneliness & isolation

- Not needed: 80%
- Need: 20%
- Met need: 25%
- Unmet need: 75%

No difference by:
- Age
- Sex
- Exposure
- Ethnicity

<table>
<thead>
<tr>
<th></th>
<th>No need</th>
<th>Need</th>
<th>Unmet Need</th>
</tr>
</thead>
<tbody>
<tr>
<td>Main partner</td>
<td>65%</td>
<td>39%</td>
<td>37%</td>
</tr>
<tr>
<td>London resident</td>
<td>47%</td>
<td>53%</td>
<td>54%</td>
</tr>
<tr>
<td>Life Satisfaction</td>
<td>8</td>
<td>6</td>
<td>5</td>
</tr>
<tr>
<td>(median out of 10)</td>
<td></td>
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<tr>
<td>Depression (ever diagnosed)</td>
<td>27%</td>
<td>61%</td>
<td>60%</td>
</tr>
</tbody>
</table>
The 4th 90

People with HIV deserve a good quality of life at all stages of life

Challenges ahead…
Good HIV care and support DOES make a difference ...

“Once you are diagnosed with HIV your self esteem goes down, your activities decline and I feel that you really need psychological, social and spiritual support for your well being.”

“Having the HIV nurse has made a massive increase to my overall emotional and physical well-being.”

“The HIV clinic is very important to manage and provide vital information to patients. This increases their confidence and quality of life.”
How do health systems ensure good quality of life for people with HIV?

- Integrated, patient-centred approach to long-term HIV care
  - **Prevention** of other poor health conditions
  - Diagnosis and treatment of other **long term conditions**
  - **Personalised care** plan
  - Integrate **mental health** services
  - Focus on **sexual and reproductive** health
  - **Involvement** of people with HIV in their care

- Combat stigma and discrimination
- Scale up involvement of HIV community
EuroQol % reporting problems: people with HIV vs gen pop

- Pain and Discomfort
- Usual Activities
- Self-care
- Mobility
- Anxiety/Depression

People with HIV
General public

24% 42% 24%
9% 26% 50%

How can cities align efforts to achieve a good standard of care for all people with HIV?