Met and unmet health, welfare and social needs of people accessing HIV services

Findings from the Positive Voices 2017 survey

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Public Health England
on behalf of the Positive Voices study group
>90,000 people accessing HIV services in the UK, vast majority on HIV treatment and undetectable

People with HIV are diverse and face a wide range of complex health and social care issues, in addition to their HIV

Their specific needs, and the extent to which these needs are currently being met is unknown

**United Kingdom**

<table>
<thead>
<tr>
<th>Target</th>
<th>Progress</th>
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</thead>
<tbody>
<tr>
<td>Aware of their HIV status</td>
<td>88%</td>
</tr>
<tr>
<td>On HIV treatment</td>
<td>96%</td>
</tr>
<tr>
<td>Virally suppressed</td>
<td>97%</td>
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</table>

1. Present national estimates of the met and unmet health and social needs of people accessing HIV services in the UK

2. Explore the areas of greatest unmet need and their contributing factors
Methods

- February – September 2017
- Nationally representative
  - Random sample from HARS
  - ~20% patients/clinic
- Clinic-based recruitment
  - Face to face, post or email
- Self-completion
  - Paper (87%) or online (13%)
- Incentive
  - £5 high street voucher
- Results:
  - 73 clinics
  - 4,424 responses
  - 51% response rate
Participant characteristics

- 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

* 2017 HIV clinic attendees, aged ≥18 resident England and Wales
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>Information about living with HIV (including websites)</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>
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<tr>
<td>Help disclosing your HIV status</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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If you were not able to get the help you needed, please tell us the reason(s) why:
Defining “Unmet need”: those who did not receive help in past year, of those who needed it

**Population**

<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>
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If you were not able to get the help you needed, please tell us the reason(s) why:
Results: What help do you need?

- HIV-RELATED NEEDS: 83% of patients with a need, 20% of needs unmet.
- HEALTH-RELATED NEEDS: 77% of patients with a need, 47% of needs unmet.
- SOCIAL AND WELFARE NEEDS: 45% of patients with a need, 62% of needs unmet.
Public Health England

HIV RELATED SERVICES
- Peer support
- Disclosure support
- Support managing LTC
- Information - living with HIV
- HIV treatment advice
- Adherence support

HEALTH SERVICES
- Drug detox or maintenance
- Chemsex support
- Stress management
- Smoking cessation
- Alcohol counselling/treatment
- Weight management
- Drug counselling
- Advice regarding sex life
- Psychologist or counsellor
- Home health services
- Family planning

SOCIAL & WELFARE SERVICES
- Loneliness or isolation
- Career skills and training
- Childcare services
- Financial advice
- Employment advice
- Legal advice
- Relationship advice
- Meal or food services
- Immigration support
- Domestic violence services
- Housing support
- Benefit claim support

% NEED (% UNMET NEED)
- HIV RELATED SERVICES
  - Peer support: 61% (47%)
  - Disclosure support: 47%
  - Support managing LTC: 29%
  - Information - living with HIV: 33%
  - HIV treatment advice: 27%
  - Adherence support: 3%

- HEALTH SERVICES
  - Drug detox or maintenance: 31%
  - Chemsex support: 31%
  - Stress management: 29%
  - Smoking cessation: 29%
  - Alcohol counselling/treatment: 27%
  - Weight management: 27%
  - Drug counselling: 27%
  - Advice regarding sex life: 27%
  - Psychologist or counsellor: 27%
  - Home health services: 27%
  - Family planning: 27%

- SOCIAL & WELFARE SERVICES
  - Loneliness or isolation: 22%
  - Career skills and training: 22%
  - Childcare services: 22%
  - Financial advice: 22%
  - Employment advice: 22%
  - Legal advice: 22%
  - Relationship advice: 22%
  - Meal or food services: 22%
  - Immigration support: 22%
  - Domestic violence services: 22%
  - Housing support: 22%
  - Benefit claim support: 22%
HIV treatment advice and information

HIV treatment advice
- Not Needed: 39%
- Need: 61%
  - Met: 93%

Information about living with HIV (including websites)
- Not Needed: 53%
- Need: 47%
  - Met: 87%

Average HIV Clinic Rating: 9.3

- Enough information: 98%
- Involved in decisions: 94%
- Supported to self-manage: 95%
- Enough time at appts: 96%
- Staff listen: 97%
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- Career skills and training
- Childcare services
- Financial advice
- Employment advice
- Legal advice
- Relationship advice
- Meal or food services
- Immigration support
- Domestic violence services
- Housing support
- Benefit claim 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
Any drugs in past 3 months: 27%

MSM reported chemsex in past 3 months: 15%
Public Health England

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% NEED

% UNMET NEED
Help dealing with loneliness and 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>Life Satisfaction</td>
<td>8</td>
<td>6</td>
<td>5</td>
</tr>
<tr>
<td>(median out of 10)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Depression</td>
<td>27%</td>
<td>61%</td>
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</tr>
<tr>
<td>(ever diagnosed)</td>
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Limitations

• Non-response bias

• Self-report does not always reflect actual need

• No specific detail on where, when, how services/help were accessed

• Limited data on why services/help were not accessed
Conclusions

• Provision of HIV-related services for those who need them is very good

• There are major gaps in the provision of social and welfare services, as well as certain health-related services

• This comprehensive needs assessment provides important data for local commissioners, health service providers and support organisations to identify gaps in service provision and inform the development of service specifications

• Further breakdowns (e.g. by risk-group, lifestyle risk behaviours, geography) are needed to inform advocacy and tailor local response
to all Positive Voices survey participants
&
staff at 73 recruiting HIV clinics

Positive Voices Study Group
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