The utility of surveillance: Public health monitoring of the HIV epidemic in the United Kingdom

Dr Valerie Delpech
Public Health England

Utility of public health monitoring

• Policy development and development
• Monitoring of public health interventions
• Inform clinical and public health guidelines
• Inform and evaluate primary prevention efforts
• Inform and set standards of care
• Better understand patient experience and satisfaction
• Planning of HIV clinical and social care services
• Commissioning of HIV services and prevention
• Public health research

Why it works

• Partnerships between clinicians, academics and public health experts
• Confidentiality and data security maintained
• Engagement of key stakeholders
• Reviewed and adapted
• Regular outputs and feedback
• Community engagement

Monitoring the HIV epidemic and our response

Routine reporting
• Testing – new diagnoses
• Clinical information – clinics and laboratories
• STI surveillance

Prevalence studies (routine and unlinked anonymous)
• STI clinics
• Antenatal
• Blood donors
• People who inject drugs

Behavioural surveillance - general population and key populations

Quality of care indicators

British HIV Doctors voted at their recent conference in London to fund the provision of anti-HIV drugs to gay men who are HIV negative so that they can protect themselves against the infection and no longer need to use condoms. This will be at the tax payers expense at a time when waiting times in Accident and Emergency Departments are at an all-time high and the average well-deserving British taxpayer is being denied deserving healthcare interventions such as hip replacements.
Numbers of new HIV diagnoses and HIV tests
England, MSM: 1999-2013


New diagnoses among heterosexual men and women by probable place of acquisition, UK

New HIV diagnoses by region of birth, MSM, UK: 1999-2013

Estimates of UK-acquired HIV infection among persons born abroad and diagnosed with HIV

A new method to assign country of HIV infection among heterosexuals born abroad and diagnosed with HIV

Proportion of heterosexuals born abroad who probably acquired HIV while living in the UK, by world region of birth: UK, 2013
New HIV diagnoses acquired by UK-born heterosexuals through sex outside the UK

Data from 2002-2010:
- 15% of UK born adults newly diagnosed with HIV reported acquiring infection abroad

Countries most commonly reported:
- Thailand, South Africa, Nigeria, Spain, Zimbabwe and the USA

Compared to adults who acquired HIV in the UK, more likely to be:
- Heterosexual
- Older
- Contact with sex workers

Antenatal screening for HIV

HIV testing coverage and uptake among heterosexuals & MSM attending sexual health clinics, by ethnicity: E&W, 2013

Monitoring of quality of HIV care

Monitoring of HIV testing

National cohort of Persons seen for HIV care

(A)ll persons attend an NHS clinic
- Annual follow up data (cd4, VL, ART) (SOPHID)
- Linked by soundex to previous years to form national cohort

Data used to inform
- Diagnosed Prev trends
- Clinical outcomes
- Testing policies
- Undiagnosed infection
- TASP
New HIV diagnoses and number of persons accessing HIV care in the United Kingdom: 2014

Treatment guidelines: proportion of adults with CD4<350 cells/mm³ receiving antiretroviral therapy: UK, 2013

Effectiveness of treatment: proportion of adults achieving viral suppression¹: UK, 2013

HIV clinical dashboards

Monitoring the first year of HIV care

Monitoring the HIV epidemic and the UK’s response

Modelling work – undiagnosed and incidence, projections, scenario setting

Use of CD4 count
• late diagnosis
• Link to care
• Incidence estimates
• Undiagnosed infection estimates
• Probable country of infection
Estimated number of people living with HIV in the UK, 2013

<table>
<thead>
<tr>
<th></th>
<th>Diagnosed</th>
<th>Undiagnosed</th>
<th>% unaware</th>
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<tbody>
<tr>
<td>Men</td>
<td>Black African ethnicity</td>
<td>8,400</td>
<td>5,250 (3,400-11,850)</td>
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<tr>
<td></td>
<td>Non-black African ethnicity</td>
<td>7,500</td>
<td>2,800 (1,600-4,800)</td>
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<tr>
<td>Women</td>
<td>Black African ethnicity</td>
<td>17,200</td>
<td>7,850 (5,300-11,600)</td>
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<tr>
<td></td>
<td>Non-black African ethnicity</td>
<td>7,950</td>
<td>2,400 (1,500-3,700)</td>
</tr>
<tr>
<td>MSM</td>
<td></td>
<td>35,300</td>
<td>7,200 (4,000-11,850)</td>
</tr>
<tr>
<td>UK total</td>
<td></td>
<td>81,700</td>
<td>26,100 (20,300-33,800)</td>
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Monitoring the HIV epidemic and the UK’s response

Linking with other databases (using limited identifiers)
- STI clinic data
- Testing data
- HIV resistance database including phylogenetics projects
- Office of national statistics – deaths ? Cancer
- TB diagnoses
- Invasive pneumococcal disease
- ?Hospitalisation data

Monitoring of deaths among PLHIV

- ‘Persons diagnosed early can expect a near normal life span’
- In 2012, death rates among persons with HIV were 3 X that of general population
Deaths among people diagnosed with HIV in the era of ART: England and Wales, 1997-2012

“Positive Voices” – Concept

1. Use SOPHID as a national sampling frame to pre-select a random sample of HIV-positive patients to receive a survey invitation

2. Recruitment when patients attend the HIV clinic for routine care

3. Responses linked to clinical data (VL, CD4, ART, resistance) in SOPHID

4. Repeated at regular intervals

Questionnaire Domains

1. HIV diagnosis and treatment
   - Testing history
   - Adherence
   - Attitudes toward ART

2. Comorbidities
   - Non-HIV related conditions
   - Medications

3. Quality of Life
   - EQ-5D
   - Functional assessment of HIV
   - Mental Health

4. Stigma and Discrimination
   - Disclosure
   - Experiences with discrimination

5. Sex & Relationships
   - Condom use
   - Number and type of partners
   - STI testing history

6. Health & Lifestyle
   - Tobacco, alcohol, and drug use
   - Body Mass Index (BMI)

7. Service Use and Satisfaction
   - Health service usage
   - Support organisation access
   - Patient experience and satisfaction

8. Sociodemographic
   - Employment
   - Education
   - Religion

Questionnaire Development

- Literature review
  - Health-related quality of life
  - HIV stigma
  - Adherence

- Use of validated tools
  - Health Survey for England (HSE)
  - UK Household Longitudinal Survey (UKHLS)
  - British Household Panel Survey (BHPS)
  - National Survey of Sexual Attitudes and Lifestyles (NATSAL)
  - Medical Monitoring Project (MMP)

- May – November 2014
- RCT design to assess best recruitment methods
- 30 HIV clinics - inside/outside London, large/small clinics. 1/3 of pop accessing HIV care.
- Sample size = 4,350 participants to invite, 27% recruited
Results - Main Demographics

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

Results: Overall health

“In general, would you say your health is?”
- No noticeable differences by age or gender and sexual risk

Satisfaction with Care – HIV specialist and GP

“Overall, how would you rate your GP/HIV specialist services?”

Disclosure

“Does your GP know your HIV status?”
- No noticeable differences by age or gender and sexual risk

“Apart from health care staff, have you told anyone that you have HIV?”
- Differences by ethnicity and gender and sexual risk exist

Disclosure to GP

Disclosure outside healthcare

95%
16%
84%

Patient experience

“If you wish, please use the space below to tell us about when you have experienced discrimination because of your HIV status.”

I had a nurse recommend to another nurse to double-glove because of my status in front of me…
- Man, 24, diagnosed 2013

When I registered with a GP, the doctors said “Oh great another POS person”, I left and complained to the practice manager still not had a response…
- Man, 33, diagnosed 2008

“At the dental clinic, I was put last on list to be attended to that day.”
- Woman, 52, diagnosed 2007

“I have had issues with GPs - they often have little or no experience with HIV+ patients and don’t have a clue about how to approach you. Its not discrimination, but a lack of experience…”
- Man, 42, diagnosed 2012

My dentist left me in agony for over a year as she didn’t want to do the extractions because of the blood…
- Man, 46, diagnosed 2010

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Positive Voices next steps

- Dissemination of findings
- Piloting of iPads in clinics
- PLHIV engagement events
- Use of Positive Voices
  - Part of routine Public health monitoring
  - Patient engagement and satisfaction – included on dashboards
  - Selected population and focused surveys (e.g., BME, women, older age)
  - Matching to HARS – rich source of clinical and self-reported information

Conclusions

- Good and timely public health monitoring drives & monitors policy and prevention and interventions at all levels
- First year of HIV diagnosis is crucial
- Monitoring of Clinical outcomes can be achieved with minimal data
- Good data collection requires a skilled public health workforce with epidemiological expertise – trust and robust confidential data systems
- Sensitive methods of collecting accurate risk information
- Work closely with modellers and statisticians to estimate undiagnosed & and incidence infections
- Engagement of people most affected at all levels

We gratefully acknowledge persons living with HIV, clinicians, health advisors, nurses, microbiologists, public health practitioners, data managers and other colleagues who contribute to the surveillance of HIV and STIs in the United Kingdom.