Improving Standards of Care in the UK

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Disclosures

- Educational grants (HIV Unit): Merck Sharp & Dohme, Gilead Sciences, Janssen, ViV Healthcare and Barts Charity
- Honoraria and travel sponsorship for lectures and advisory board contributions
- Member of the BHIVA Guidelines Subcommittee (2008–2017)
- Chair and executive trustee of BHIVA
- Not a patent holder or a shareholder
- No disclosures for spouse or family members
Progress toward achieving the third 90:
Target 3: 90% of those on ART virally suppressed (n=35)

Source: UNAIDS data 2017

UK progress toward 90/90/90 targets for 2020

87% of which Aware of their HIV status
96% of which On HIV treatment
94% Virally suppressed

Source: Public Health England (2016) 'HIV in the UK'

www.avert.org

London

90% Diagnosed
97% On treatment
97% Undetectable

*VL <200 c/mL
Achieving success

Examining our journey to improve the cascade of care

- All numbers have been rounded to the nearest 100.
- All numbers are from the National HIV and AIDS Reporting System (HARS) directly and have been adjusted for missing information.
- Virally suppressed was defined as having the latest reported viral load (VL) <200 copies/ml

Peter Principle Corollary
If at first you don't succeed, try something else.
Assessing standards against guidelines

Epidemiology

Guidelines

Audit

Data from national surveillance on HIV epidemic

Auditble outcomes from guidelines

What are our services delivering? What should they be like? How can we improve?

Improving care in the UK - two methods

1. BHIVA annual national audit
2. BHIVA Standards for HIV clinical care

Routine monitoring and assessment of adults with HIV
BHIVA national audit 2015
Anita Mailay on behalf of BHIVA
Audit and Standards Sub-Committee

Standards of Care for People living with HIV 2015
Audit: evaluates a process not an outcome

- Audit: a snapshot in time
- Evaluates service delivery
- All clinics participate
- Not = national surveillance
- Voluntary
- Questions derived from guideline auditat issues
- Data collection feasible for clinics

Tools: Data collection

<table>
<thead>
<tr>
<th>BHIVA HIV monitoring and assessment self-audit tool</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient 1</td>
</tr>
<tr>
<td>Date on which audit data was retrieved from patient's record (dd/mm/yy, if required)</td>
</tr>
<tr>
<td>Date on which patient was last seen and reviewed by a clinician (dd/mm/yy, if not just bloods taken)</td>
</tr>
<tr>
<td>Age:</td>
</tr>
<tr>
<td>Ethnicity</td>
</tr>
<tr>
<td>Exposure risk for HIV</td>
</tr>
<tr>
<td>Latest CD4 in CD4/mm³?</td>
</tr>
<tr>
<td>Does the patient have a current ART prescription?</td>
</tr>
<tr>
<td>Does current regimen include tenofovir?</td>
</tr>
<tr>
<td>Has HIV resistance testing ever been performed?</td>
</tr>
<tr>
<td>Stable on ART and long-term suppressed?</td>
</tr>
<tr>
<td>When was HIV viral load (VL) last measured (date sample was taken or leave blank if not recorded in past 2 years)?</td>
</tr>
<tr>
<td>When was ART adherence last assessed (give date or leave blank if not recorded within past 2 years)?</td>
</tr>
<tr>
<td>Date list of all medication list recorded (or recorded that on no medication other than ART, give date or leave blank if not recorded in past 2 years)?</td>
</tr>
<tr>
<td>Hepatitis A (HepA) status:</td>
</tr>
<tr>
<td>serum anti-HepA, icluding status</td>
</tr>
<tr>
<td>Hepatitis B (HepB) surface antibody, anti-Hbs, status</td>
</tr>
<tr>
<td>Core antibody, anti-Hbc, status</td>
</tr>
<tr>
<td>When was the patient's anti-Hbs titre last measured (give date sample was taken)?</td>
</tr>
<tr>
<td>Hepatitis C (HepC) antibody status:</td>
</tr>
<tr>
<td>When was HepC antibody testing last done (give date sample was taken)?</td>
</tr>
<tr>
<td>When was HepC RNA last tested?</td>
</tr>
<tr>
<td>Date 6th year (CD) risk calculated (give date or leave blank if no test result known or has established CD)</td>
</tr>
<tr>
<td>When was smoking history last recorded (give date or leave blank if no record)?</td>
</tr>
<tr>
<td>Smoking status:</td>
</tr>
<tr>
<td>Has a smoking cessation service been offered?</td>
</tr>
<tr>
<td>When was the patient's blood pressure (BP) last recorded (give date or leave blank if no record)?</td>
</tr>
<tr>
<td>When was systolic last done in sitting position (mmHg) last measured (give date or leave blank if no record)?</td>
</tr>
<tr>
<td>When was diaastolic last measured (give date or leave blank if no record)?</td>
</tr>
</tbody>
</table>
Confidential feedback to each clinic: compared with national figures

<table>
<thead>
<tr>
<th>Scenario leading to death</th>
<th>All centres</th>
<th>Centre 752003</th>
</tr>
</thead>
<tbody>
<tr>
<td>Multi-drug resistant HIV - run out of treatment options</td>
<td>11</td>
<td>3%</td>
</tr>
<tr>
<td>Being successfully treated for HIV but suffered a catastrophic event (e.g. adverse reaction)</td>
<td>7</td>
<td>2%</td>
</tr>
<tr>
<td>Under care but had untreated HIV-related complication</td>
<td>61</td>
<td>16%</td>
</tr>
<tr>
<td>Under care but had chosen not to receive treatment</td>
<td>18</td>
<td>6%</td>
</tr>
<tr>
<td>Under care but treatment ineffective due to poor adherence</td>
<td>26</td>
<td>7%</td>
</tr>
<tr>
<td>Under care but unable to take treatment due to toxicity/intolerance</td>
<td>1</td>
<td>0%</td>
</tr>
<tr>
<td>Not treated or had treatment delayed because of ineligibility for NHS care</td>
<td>0</td>
<td>0%</td>
</tr>
<tr>
<td>Known to have HIV but not under care, re-presented too late for effective treatment</td>
<td>12</td>
<td>3%</td>
</tr>
<tr>
<td>Diagnosed with HIV too late for effective treatment</td>
<td>93</td>
<td>24%</td>
</tr>
<tr>
<td>Died in community without seeking care</td>
<td>1</td>
<td>0%</td>
</tr>
<tr>
<td>Death not directly related to HIV</td>
<td>123</td>
<td>32%</td>
</tr>
<tr>
<td>None of above</td>
<td>8</td>
<td>2%</td>
</tr>
<tr>
<td>Not stated</td>
<td>25</td>
<td>6%</td>
</tr>
<tr>
<td>Total</td>
<td>367</td>
<td>100%</td>
</tr>
</tbody>
</table>

Feedback: dashboard for grouped outcomes

Audit on Monitoring patients with HIV
Oh dear….

Audit on Monitoring patients with HIV

How do we improve our poor performance?

Audit on Monitoring patients with HIV
Audit Conclusions-sent to each centre

Main Conclusion and recommendations from MORTALITY audit:
Late diagnosis accounted for 24% of deaths overall and 35% of HIV related deaths
Causes not related to HIV accounted for 32% of deaths

National Dissemination

• National presentation
• Given by doctor in training
• Embedding standard of care approach

People with diagnosed HIV infection apparently not in care
BHIVA in collaboration with Health Protection Agency
Psychological well-being and support, and use of alcohol and recreational drugs

BHIVA National Clinical Audit 2017

Dr Sarah Parry
Trainee Doctor in HIV/GUM

On behalf of the BHIVA
Audit and Standards Sub-committee

Aim

To assess adherence to standards and guidelines regarding psychological support and alcohol and recreational drug use, including chemsex.
Methods

1. Survey of HIV services’ provision and care pathways relating to psychological support and substance use

2. Case-note review of 40 adult HIV patients per service covering:
   • Whether psychological well-being/mental health and substance use had been assessed within last 18 months
   • If problems identified, whether support was offered/provided

Rapid Feedback

Participating sites were invited to request a rapid feedback report after submitting case note review data for 40 individuals:

• 48 out of 119 sites taking part in the case note review requested this
• Reports were sent within 1-2 working days
Case note review

4486 adults (16 or over) who attended for HIV care during 2016 and/or 2017

Assessment by clinic proforma/standard procedure

- Psychological well-being/mental health: 49% (All patients), 51% (Some groups), 73% (Not routine)
- Alcohol use: 49% (All patients), 38% (Some groups), 73% (Not routine)
- Recreational drugs: 32% (All patients), 31% (Some groups), 67% (Not routine)
- Chemsex: 13% (All patients), 8% (Some groups), 34% (Not routine)
Provision of psychological support

Summary of outcomes: service provision

- 49% of HIV services had an identified clinical lead for psychological support
- Documented care pathways for mental health, alcohol and drugs were reported by 53%, 38% and 36% of HIV services respectively, but more than 80% of services can refer patients directly
Summary of outcomes: assessment

- Rates of routine assessment within the previous 18 months were:
  - 66.0% of patients for psychological well-being/mental health
  - 68.0% for alcohol use
  - 58.4% for recreational drugs
  - 16.8% (26.5% of MSM) for chemsex

- These varied widely but were higher when included in the service’s proforma/standard procedure

Summary of outcomes: psychological status

Among individuals assessed:
- 59.4 were coping well
- 17.4% had some need for info/support
- 14.6% had significant distress or psychological support need
- 5.1% were likely to have a diagnosable psychiatric illness

This varied widely between services, but sites having a clinical lead or routinely using an assessment tool identified higher levels of need
Summary of outcomes: substance use

Among individuals assessed:

- The rate of problematic alcohol use was lower than expected in comparison with the general population
- Of individuals engaging in chemsex, 53% were identified as involved in problematic use
- A small number of individuals who injected drugs were not considered to have a problem

Summary of outcomes: support provided

- Nearly all individuals identified with psychological problems were offered or already receiving support
- Around 90% of individuals identified with recreational drug/chemsex problems were offered or already receiving support
- For alcohol, this figure was only 69%

*However these findings might be artefacts if provision was interpreted as evidence of documented need*
Recommendations to HIV services

HIV services should:

• Review their own results
• Identify a clinical lead for psychological support
• Develop agreed care pathways
• Prospectively look for possible psychological support needs on a routine basis, via a standard clinic proforma or procedure
• Adopt a systematic approach to alcohol and recreational drugs assessment and support, including chemsex

Recommendations to BHIVA

BHIVA should explore the scope for guidance on methods for routine assessment of psychological support needs and substance use.

2016 monitoring guidelines suggest:

• The wellness thermometer can be useful as an aid to communication.  

• Pre-consultation screening tools enable patients’ agendas to shape the consultation and enable better communication of any concerns.
Recommendations to BHIVA

This might include recommending specific tools, e.g.

**EACS two sentences:**
- Have you often felt depressed, sad or without hope in the last few months?
- Have you lost interest in activities that you usually enjoy?

**PHQ2:**
Over the past 2 weeks, how often have you been bothered by any of the following problems?
- Little interest or pleasure in doing things
- Feeling down, depressed or hopeless

**GAD2:**
Over the last 2 weeks, how often have you been bothered by the following problems?
- Feeling nervous, anxious, or on edge
- Not being able to stop or control worrying

**BHIVA Standards of Care**

**Content of Standards**

- 8 quality Standards, covering the care that any adult living with HIV in the UK should expect to receive.
- Each one presents a rationale, quality statements and measurable and auditable outcomes.
- Three new sections have been introduced looking at HIV prevention, stigma and well-being, and HIV across the life course.
- **HIV Prevention - Standard 1, Testing, diagnosis and prevention:**
- **Stigma and wellbeing - Standard 2, Person-centred care**
- **HIV across the life course - Standard 7**

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**Press Release**

- BHIVA Standards Co-Chair, Ann Sullivan:
  - "Patients have had a key role in every stage ....actively involved in all writing groups; responding ....recommending, volunteering for ....organising the real representation seen in the Standards' imagery to deliver improved outcomes for people living with HIV in the areas that are important to them."

- BHIVA Chair, Chloe Orkin comments:
  - "This third set of BHIVA Standards has been developed....with the aim of delivering high quality services to achieve the best possible outcomes.
  - "......we are proud to say that outcomes for people living with HIV in the UK are among the best in the world.
  - "...we must manage the complex co-morbidities of an ageing HIV population but on the other we welcome the very positive impact of effective medications on HIV transmission. Increased testing, alongside prevention interventions such as pre-exposure prophylaxis (PrEP)....
  - "We hope that these new Standards will provide a framework to inform and support commissioning decisions both within and outside the NHS....to inform people living with HIV, and those who advocate for them, about the care they should expect to receive when they access HIV services."

Response to public consultation

• Following the recent launch of the Standards of Care the use of the word ‘negligible’ on U=U was replaced with more accessible phrases to convey this important public health message and have included the full statement for ease of reference.

• "There should be no doubt that a person with sustained, undetectable levels of HIV virus in their blood cannot transmit HIV to their sexual partners,” Chloe Orkin, BHIVA Chair.


Foster Engagement
Variation between services in assessment

Proportion of individuals for whom asked/recorded within each participating service

- Psychological well-being
- Alcohol
- Recreational drugs
- Recreational drugs (MSM only)
- Chemsex
- Chemsex (MSM only)
Psychological status by whether service has identified clinical lead

Proportion of patients identified with significant need or probable psychiatric illness