Key findings and recommendations

BHIVA’s main national audit project for 2019 focused on management pathways from diagnosis of HIV to starting antiretroviral therapy (ART). Key findings were that:

- Nationally, only 67.7% of individuals were seen by an HIV specialist clinician within 2 weeks of their initial positive/reactive HIV test, which is the standard of care, and this varied widely between sites. Delays were commonest among individuals tested in general practice or in non-GUM/HIV outpatient departments.

- In terms of topics addressed at, or before, the first discussion of ART initiation, benefits of ART to the individual and partner notification were covered for a large majority of individuals (85.8% and 85.7%, respectively).

- Evidence that effective viral load suppression by ART means the person cannot transmit HIV sexually (‘undetectable equals untransmittable’ or U=U) was less often addressed (56.6%), as was availability of peer/community support (61.4%). There was wide variation between sites for both.

- Most individuals started ART promptly. Among all audited individuals, 83.0% met the NHS England measure of starting within 91 days of diagnosis. Excluding those with missing data, 51.4% started within 4 weeks and 79.5% within 8 weeks of the initial positive/reactive test.

Recommendations

In the light of these findings, BHIVA recommends that specialist HIV services should:

- Ensure pathways into HIV care are readily accessible with clear guidance for all healthcare professionals and peer/community support organisations. This should be kept updated and communicated to colleagues, especially general practice.

- Routinely discuss and document all relevant topics, including U=U and availability of peer/community support, with newly diagnosed individuals.

- Review individuals who have not started ART within 6–8 weeks of diagnosis to identify possible support needs.

Management pathways for new HIV diagnoses

The main audit for 2019 focused on timelines from HIV diagnosis to assessment by a specialist HIV clinician and to ART initiation, based on case-note review of newly diagnosed adults (age 16 or over) who were first assessed between 1 January 2018 and 31 March 2019. Participation was good, with data being provided for 2281 individuals from 132 clinic sites, and a further three sites reporting no eligible individuals.

Standards of care for people living with HIV (2013 and 2018) recommend that newly diagnosed people should have their HIV status fully assessed within 2 weeks of testing HIV positive, so it is disappointing that the audit found that only 67.7% of individuals were seen by an HIV specialist clinician within this period (Table 1). Delays were more common among individuals whose initial test was performed in general practice or outpatient settings other than GUM/sexual health/HIV (Figure 1).

Table 2 shows the proportions of individuals for whom different topics were addressed at, or before, the first discussion of ART initiation. It is of concern that U=U and availability of peer/community support were addressed for only 56.6% and 61.4% of individuals, respectively, with wide variation between sites.

There is no specified standard for the time to ART initiation as this should be guided by the individual’s readiness to start, but the proportion starting within 91 days (13 weeks) of diagnosis is included as an indicator in NHS England’s HIV quality dashboard. Audited times were as shown in Table 1, and 83.0% of all individuals met this NHS England measure. Excluding those with missing data, 51.4% started within 4 weeks and 79.5% within 8 weeks of the initial positive/reactive test. As expected, individuals with primary or advanced HIV infection were more likely to start ART within 4 weeks of diagnosis. Gender, ethnicity and age were not associated with time to ART initiation.

Only 118 individuals started ART later than 12 weeks after diagnosis. One or more reasons
for delay were reported for 93 (78.8%) of these as follows: individual did not attend booked appointment(s) 34 (28.8%); individual did not wish to start ART when first offered 31 (26.3%); delayed for clinical reasons because of concomitant illness/medication 21 (17.8%); individual postponed or re-scheduled appointment(s)/attendance(s) 20 (16.9%); time to receive results of tests 12 (10.2%); virtual clinic approval required for non-standard regimen 3 (2.5%); other reason(s) 15 (12.7%).

Among 141 individuals who had not started ART at the reporting site by the time of audit, 62 had definitely, or probably, done so elsewhere, leaving 79 (3.5%) who had not started ART. Of these, six (0.3%) had fewer than 13 weeks’ follow-up time from testing positive to audit data submission.

Investigation of late diagnoses
A standardised process for investigating individuals diagnosed with advanced HIV (CD4 T cell count <200 cells/mm³) was successfully piloted in 15 clinical services. Discussions are in progress with NHS England regarding roll-out of this process, which involves serious incident reviews in cases where serious harm results from delayed diagnosis and clear or likely missed opportunities for earlier testing have occurred, and lighter-touch serious learning events in less severe cases.

Quality improvement and site-level performance across successive audits
In a new departure, BHIVA has investigated whether individual clinical services perform consistently well or poorly across multiple outcomes and successive audits and provided feedback on this to support local quality improvement. Services that participated in the 2018 audit of monitoring of older adults with HIV were sent reports including a ‘heatmap’ graphic showing their comparative performance across that audit, the 2017 audit of recording of psychological wellbeing and substance use, and the 2015 audit of routine monitoring. The 2016 audit was omitted because it was more process-focused.

In addition, a survey was conducted to assess quality improvement following the 2017 audit. (please see www.bhiva.org/NationalAuditReports) Although the response rate was low (45.5%), nearly all responding sites had reviewed the audit findings in a team meeting and most had planned or introduced service changes as a result. There were net positive changes in relation to specific recommendations from the audit, but some services also reported negative changes.

Standards of care for people living with HIV
Following the publication of new evidence-based Standards of care for people living with HIV 2018, BHIVA has worked with the UK-CAB peer-led network of community treatment activists to produce a patient accessible version of the standards, which is nearing completion. This has been supported by the MAC AIDS Fund.

Mortality review
BHIVA has agreed to collaborate with Public Health England to extend the existing London HIV Mortality Review across the UK, and, subject to Caldicott approval, this should begin in the near future. Participation will be voluntary, but the Audit and Standards subcommittee expects that clinical services will wish to take part in order to meet the Standards of care for people living with HIV 2018 recommendation to review all deaths among people known to have HIV.

Table 1. Times from HIV diagnosis to specialist assessment and ART initiation (numbers and percentages of audited individuals)

<table>
<thead>
<tr>
<th>Time from initial positive/reactive HIV test (weeks)</th>
<th>National number (%)</th>
<th>Median (interquartile range) for individual sites (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>To first being seen by an HIV specialist clinician:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Within 2</td>
<td>1544 (67.7)</td>
<td>73 (58–87)</td>
</tr>
<tr>
<td>Within 4 (cumulative)</td>
<td>1896 (83.1)</td>
<td>88 (80–100)</td>
</tr>
<tr>
<td>Within 6 (cumulative)</td>
<td>2022 (88.6)</td>
<td>93 (85–100)</td>
</tr>
<tr>
<td>Longer than 6</td>
<td>113 (5.0)</td>
<td>0 (0–5)</td>
</tr>
<tr>
<td>Missing data</td>
<td>146 (6.4)</td>
<td>0 (0–8)</td>
</tr>
<tr>
<td><strong>To ART initiation:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Within 4</td>
<td>1099 (48.2)</td>
<td>49 (28–60)</td>
</tr>
<tr>
<td>Within 8 (cumulative)</td>
<td>1700 (74.5)</td>
<td>78 (67–89)</td>
</tr>
<tr>
<td>Within 12 (cumulative)</td>
<td>1879 (82.4)</td>
<td>86 (78–95)</td>
</tr>
<tr>
<td>Within 13 (cumulative, NHS England 91-day measure)</td>
<td>1894 (83.0)</td>
<td>87 (78–95)</td>
</tr>
<tr>
<td>Longer than 13</td>
<td>103 (4.5)</td>
<td>0 (0–5)</td>
</tr>
<tr>
<td>ART not initiated at reporting site by time of audit</td>
<td>141 (6.2)</td>
<td>3 (0–10)</td>
</tr>
<tr>
<td>Missing data</td>
<td>143 (6.3)</td>
<td>0 (0–8)</td>
</tr>
</tbody>
</table>
Table 2. Numbers and percentages of audited individuals for whom topics were documented as covered at, or before, the first discussion of ART initiation

<table>
<thead>
<tr>
<th>Topic</th>
<th>National number (%)</th>
<th>Median (interquartile range) for individual sites (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Benefits of ART to individual</td>
<td>1957 (85.8)</td>
<td>92 (79–100)</td>
</tr>
<tr>
<td>Partner notification</td>
<td>1954 (85.7)</td>
<td>93 (83–100)</td>
</tr>
<tr>
<td>Evidence that viral load suppression on ART means person cannot transmit HIV to sexual partners, i.e. U=U</td>
<td>1290 (56.6)</td>
<td>56 (35–84)</td>
</tr>
<tr>
<td>Availability of peer/community support</td>
<td>1401 (61.4)</td>
<td>65 (44–86)</td>
</tr>
</tbody>
</table>

Figure 1. Variation in time from initial positive/reactive HIV test to being first seen by an HIV specialist clinician according to where test was conducted. Bars show median and upper and lower quartiles

Wellbeing and patient-reported outcome measures (PROMs)
BHIVA is continuing to support the development of a patient-reported outcome measure (PROM) for assessing quality of life among people with HIV, led by Prof R Harding. Funding is being sought for implementation of the PROM in a number of demonstration sites, including its integration into existing clinical data systems.

2020 audit
Planning is in progress for a national case-note review audit of HIV and hepatitis C co-infection, accompanied by a survey of clinic policy and practice regarding retention of HIV patients in care.
Publications

Publication and feedback are an essential part of the audit cycle, to enable clinicians and others to reflect on findings and change practice if necessary. The subcommittee sends each clinical service a confidential summary of its own results with aggregated data for comparison, as well as presenting national results at conferences and on the BHIVA website (www.bhiva.org).

The subcommittee also seeks to publish its major findings as peer-reviewed articles, and to make these available on an open access basis where feasible. Articles include:


Further Information

Details of previous BHIVA audits together with specimen questionnaires, findings and reports, the list of articles and further resources are available on the BHIVA website www.bhiva.org/Clinical-Audits

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