Taking action on late diagnoses

Survey of “look back” reviews and audit of individuals diagnosed with advanced HIV
Background

Late HIV diagnosis remains a serious problem – in 2014 40% of newly diagnosed adults had CD4 <350 cells/mm$^3$

BHIVA standards (2013) state:

- All HIV services should undertake a review of all patients presenting to care with advanced immunosuppression (CD4 count <200 cells/mm$^3$ or AIDS diagnosis), with “look back” of previous engagement with health care services. A summary should be provided to commissioners to aid greater understanding for interventions which can be implemented to reduce late diagnosis annually
In 2015 BHIVA published *Recording and investigation of late HIV diagnoses: good practice position statement*:

- Advice for HIV clinical services on ways of conducting “look back” reviews of late diagnoses
- To identify and learn from possible missed earlier opportunities for testing
Methods

- Survey to assess how many HIV services have conducted “look back” reviews, methods used, and impact
- Audit of up to 10 individuals per site diagnosed with advanced HIV (CD4 <200 cells/mm³) during 2015 and 2016 up to audit date
Participation

- 129 sites completed the survey
- 135 sites submitted audit data for 773 late diagnosed individuals
- A further 4 sites reported that they had no eligible patients
Conduct of “look back” reviews

58 (45%) sites had taken part in a planned, systematic exercise to review previous health care use by late diagnosed individuals:

- 53 review within own service/organisation*
- 2 as part of multi-organisation or regional review
- 2 both*
- 1 not answered

*The rest of the survey data is based on the 55 reviews within the respondent’s own service/organisation.
Inclusion in reviews

- 20 (36%) sites: all new diagnoses, without selection
- 25 (45%): low CD4 at diagnosis
- 6 (11%): low CD4 or symptomatic disease
- 4 (7%): symptomatic disease only
Of 21 sites reporting one-off reviews, 14 had done one in 2014-16, 6 earlier and 1 did not state when.
Data sources for review

- Patient-reported history of previous healthcare use: 78%
- Record held within this hospital/organisation: 87%
- Info requested from GP: 42%
- Info requested from outside secondary care provider: 22%
- Info re GP care via NHS data spine/automated system: 9%
- Info re secondary care via NHS data spine/automated system: 11%
- NHS summary care record: 7%
- Other: 11%
Costs associated with late diagnoses

- 8 (14.5%) of reviews had involved some attempt at quantifying avoidable financial costs resulting from missed/late diagnosis of HIV

Methods included applying standard reference costs to types of attendance/admission
Improving HIV testing practice

Areas for improvement were identified in:

- Secondary care: by 80% of sites conducting reviews
- Primary care: by 76%
- Community test sites/other non-clinical settings: by 29%

Only 8 of 55 sites conducting reviews reported no areas for improvement
Secondary care areas for improvement mentioned by respondents for more than 10% of reviews:

- Emergency/A&E
- Medical admissions
- Haematology
- Gastroenterology
- Respiratory medicine
- Internal medicine
- Dermatology
## Data sources and areas for improvement in secondary care

<table>
<thead>
<tr>
<th>Review used sources including:</th>
<th>Number of sites</th>
<th>Number (%) finding areas for improvement in secondary care</th>
</tr>
</thead>
<tbody>
<tr>
<td>Record within trust/organisation AND information requested from external secondary service(s)</td>
<td>12</td>
<td>12 (100)</td>
</tr>
<tr>
<td>Record within trust/organisation</td>
<td>36</td>
<td>30 (83)</td>
</tr>
<tr>
<td>Neither (e.g., patient-reported histories only)</td>
<td>7</td>
<td>2 (29)</td>
</tr>
</tbody>
</table>
### Data sources and areas for improvement in primary care

<table>
<thead>
<tr>
<th>Review used sources including:</th>
<th>Number of sites</th>
<th>Number (%) finding areas for improvement in primary care</th>
</tr>
</thead>
<tbody>
<tr>
<td>Information requested from GPs</td>
<td>23</td>
<td>17 (74)</td>
</tr>
<tr>
<td>Information not requested from GPs (e.g. patient-reported histories and/or trust/organisation records only)</td>
<td>32</td>
<td>25 (78)</td>
</tr>
</tbody>
</table>
Value of data sources:

- Including secondary care data in reviews appears to add value in identifying areas for improvement in secondary care.
- Requesting information from GPs does *not* appear to add value in identifying areas for improvement in primary care.
- NHS data spine/automated systems could not be assessed as few sites used these, and did so together with other data sources.
Action based on review findings

- Raise in grand rounds or similar
- Informal discussion
- Advocate routine testing
- Seek changes in GP training
- Seek changes in junior Dr induction
- Involve commissioners
- Introduce IT system prompt
- Critical/serious untoward incident report
- Root cause analysis
- Report to clinical senate

Key: Blue bars/bottom axis: number of sites taking action; Red dots/top axis: of sites taking action, percentage rating it 4 or 5 out of 5 for effectiveness.
Audit of individuals diagnosed with advanced HIV

773 adults with CD4 <200 cells/mm$^3$ at/shortly after diagnosis in 2015-6
<table>
<thead>
<tr>
<th>Type</th>
<th>Number</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>557</td>
<td>72.1</td>
</tr>
<tr>
<td>Female</td>
<td>213</td>
<td>27.6</td>
</tr>
<tr>
<td>Trans</td>
<td>2</td>
<td>0.3</td>
</tr>
<tr>
<td>Not stated</td>
<td>1</td>
<td>0.1</td>
</tr>
<tr>
<td>MSM</td>
<td>288</td>
<td>37.3</td>
</tr>
<tr>
<td>Heterosexual</td>
<td>430</td>
<td>55.6</td>
</tr>
<tr>
<td>IDU</td>
<td>16</td>
<td>2.1</td>
</tr>
<tr>
<td>Other</td>
<td>6</td>
<td>0.8</td>
</tr>
<tr>
<td>Not known/not stated</td>
<td>33</td>
<td>4.3</td>
</tr>
</tbody>
</table>
## Migration to UK after living abroad

<table>
<thead>
<tr>
<th></th>
<th>Number</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Non-migrant</td>
<td>378</td>
<td>48.9</td>
</tr>
<tr>
<td>Arrived &gt;2 years before diagnosis</td>
<td>251</td>
<td>32.5</td>
</tr>
<tr>
<td>Arrived 1-2 years before diagnosis</td>
<td>28</td>
<td>3.6</td>
</tr>
<tr>
<td>Arrived 6 months-1 year before diagnosis</td>
<td>19</td>
<td>2.5</td>
</tr>
<tr>
<td>Arrived &lt;6 months before diagnosis</td>
<td>38</td>
<td>4.9</td>
</tr>
<tr>
<td>Migrant, arrival date not known/reported</td>
<td>35</td>
<td>4.5</td>
</tr>
<tr>
<td>Not known/reported whether migrant</td>
<td>24</td>
<td>3.1</td>
</tr>
</tbody>
</table>
## Place of diagnosis

<table>
<thead>
<tr>
<th></th>
<th>Number</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>In-patient</td>
<td>240</td>
<td>31.0</td>
</tr>
<tr>
<td>GUM/HIV/sexual health clinic</td>
<td>182</td>
<td>23.5</td>
</tr>
<tr>
<td>General practice</td>
<td>117</td>
<td>15.1</td>
</tr>
<tr>
<td>Out-patients (not GUM/HIV/sexual health)</td>
<td>117</td>
<td>15.1</td>
</tr>
<tr>
<td>A&amp;E or admissions unit</td>
<td>34</td>
<td>4.4</td>
</tr>
<tr>
<td>Antenatal clinic</td>
<td>21</td>
<td>2.7</td>
</tr>
<tr>
<td>Home test/home sampling</td>
<td>12</td>
<td>1.6</td>
</tr>
<tr>
<td>Community HIV test service</td>
<td>8</td>
<td>1.0</td>
</tr>
<tr>
<td>Other</td>
<td>36</td>
<td>4.7</td>
</tr>
<tr>
<td>Not stated</td>
<td>6</td>
<td>0.8</td>
</tr>
</tbody>
</table>

676 (87.5%) were registered with a GP at time of diagnosis.
Information in record re health at diagnosis and during previous 2 years

- History as reported by patient once diagnosed: 87%
- List of prescribed medication at time of diagnosis*: 58%
- Hospital/trust record re non-HIV services: 32%
- GP letters/reports: 22%
- Letters/reports from other secondary/specialist services: 13%

*Or, confirmation that the individual was not receiving prescribed medication.
Information recorded about service use in 2 years preceding diagnosis

In-patient

Out-patients

General practice
Earlier missed opportunities for diagnosis

- 257 (33.2%): documented in record
- 100 (12.9%): not documented, but identified in retrospect at audit

46.2% could have been diagnosed sooner

Most missed opportunities were recognised and documented before audit
Circumstances of documented missed opportunities

- 182 (70.8%) clinician did not offer test when it would have been appropriate
- 20 (7.8%) patient declined offer of test
- 12 (4.7%) both of above on different occasions
- 43 (16.7%) unclear
Action on documented missed opportunities

- 128 (49.8%) informal discussion
- 45 (17.5%) presented as case at grand rounds or similar
- 14 (5.4%) serious untoward incident procedure and/or root cause analysis
- 43 (16.7%) other action
- 87 (33.8%) no reported action.
Learning from 257 documented missed opportunities

- 34 (13.2%) respondent was aware of change in HIV testing practice arising “wholly or partly from learning based on this patient’s case”
- 144 (56.0%) no such change
- 75 (28.8%) not sure
- 5 (1.9%) not answered
Reflections

Gastroenterologists now routinely consider HIV test with IBD/chronic diarrhoea

Provided excellent results for routine HIV testing in TB patients and hepatology (and some gastroenterology) clinics

A drop in the ocean.. Need to sustain these activities

Difficult to assess outcomes in other settings

Problems – lack of HV awareness. Success – 98% uptake in ID

More offer of HIV test on acute medical admissions

Subsequent patient admitted with a similar presentation was offered an HIV test
Summary

- Most services had *not* done an organised “look back” review of late diagnoses
- Most such reviews relied on patient-reported history plus records held within the hospital/trust/organisation
- Despite this limited data, nearly all reviews found areas for improvement in HIV testing
Summary

- Recent migration accounted for only a small proportion of individuals diagnosed with advanced HIV (CD4 <200 cells/mm³)
- Previous healthcare use was reasonably well-recorded for such individuals
Summary

- A third of individuals diagnosed with advanced HIV had earlier missed opportunities for diagnosis documented in the record.

- A further 13% were assessed in retrospect at audit as having had earlier missed opportunities, giving a total of 46%.
Summary

- Most missed opportunities were due to clinicians not offering an HIV test, rather than the patient declining one.
- Some form of action was taken for two thirds of individuals with missed opportunities documented at the time of diagnosis.
Conclusions

Action can be effective in improving HIV testing practice, although this is not always easy.

Responses suggest that measures which seek to embed better practice might be perceived as more effective, eg:

- Changes in junior doctor induction
- Working with commissioners to include testing in contracts and pathways/protocols
- Possibly changes in GP training
Conclusions

- Organised review of late diagnoses may be better able to support system change than ad hoc action based on individual cases
- Persistence is necessary
Recommendations

- All HIV services should adopt a systematic approach to reviewing previous healthcare use among late diagnosed individuals and act on findings
- This should be based on patient-reported history, plus if possible records held within the organisation and/or information obtained from other secondary care services
- Although not studied explicitly, it seems reasonable to encourage multi-organisation or regional reviews
Acknowledgements

Thanks to all clinical services which provided data.

BHIVA Audit and Standards Sub-Committee:

- B Angus, D Asboe, F Burns, R Byrne, D Chadwick, D Churchill, H Curtis (co-ordinator), V Delpech, K Doerholt, A Freedman (chair), A Molloy, J Musonda, N Naous, O Olarinde, E Ong, S Raffe, C Sabin, A Sullivan.
Improving access to seasonal influenza vaccine

Survey of clinic activity relating to flu vaccination for adults with HIV
Background

- Annual seasonal influenza (flu) vaccination is recommended for adults with HIV infection
- 2008 BHIVA guidelines proposed a target of 95% for offer of annual flu vaccine to individuals with HIV
- In the 2015 BHIVA audit of routine monitoring, 21.1% of audited patients had received flu vaccine and a further 36.2% had been advised to obtain this from a GP
Relevant issues include that flu vaccination is:

- Seasonal (in autumn) rather than annual
- Usually administered in primary care and not always available in specialist HIV clinics
Method and participation

135 HIV specialist clinical services completed an online survey about their practice in enabling adults with HIV to access flu vaccine
Availability of flu vaccine

- Routinely offered in HIV clinic
- Patients encouraged to attend elsewhere, but some vaccine stocked
- Patients encouraged to attend elsewhere and vaccine not stocked
- Other
## Action to inform GPs about HIV patients’ eligibility for flu vaccine

<table>
<thead>
<tr>
<th>Action</th>
<th>All clinics</th>
<th>Clinics which do not stock vaccine</th>
</tr>
</thead>
<tbody>
<tr>
<td>Write to GP seasonally, unless consent refused</td>
<td>46 (34%)</td>
<td>19 (39%)</td>
</tr>
<tr>
<td>Mention flu vaccine in standard GP letter</td>
<td>70 (52%)</td>
<td>26 (54%)</td>
</tr>
<tr>
<td>Inform GP re flu vaccine eligibility for newly diagnosed patients, unless consent refused</td>
<td>45 (33%)</td>
<td>21 (44%)</td>
</tr>
<tr>
<td>Any reported HIV clinic action to inform GP</td>
<td>114 (84%)</td>
<td>44 (92%)</td>
</tr>
</tbody>
</table>
## Action to inform patients

<table>
<thead>
<tr>
<th>Action</th>
<th>All clinics</th>
</tr>
</thead>
<tbody>
<tr>
<td>Contact patients seasonally, unless consent refused</td>
<td>22 (16%)</td>
</tr>
<tr>
<td>Advise if attending for routine bloods during season</td>
<td>97 (72%)</td>
</tr>
<tr>
<td>Advise if attending for clinician review during season</td>
<td>117 (87%)</td>
</tr>
<tr>
<td>Include in protocol for annual clinician review, regardless of time of year</td>
<td>77 (57%)</td>
</tr>
<tr>
<td>Include in protocol for new patient assessment</td>
<td>80 (59%)</td>
</tr>
<tr>
<td>Offer note/certificate of eligibility</td>
<td>5 (4%)</td>
</tr>
<tr>
<td>Display posters/leaflets</td>
<td>32 (24%)</td>
</tr>
</tbody>
</table>
Recording

- 73 (54%) of clinics have a system and aim to routinely record when HIV patients are given advice about flu vaccine
- 64 (47%) of clinics have a system and aim to routinely record uptake of flu vaccine
New activity in 2015/6 season

- 28 (21%) services changed procedures or practice in autumn 2015/winter 2016
- In one case commissioners withdrew funding for vaccine in clinic, leaving 27 (20%) who did so by choice
- 15 (11%) were influenced by the 2015 BHIVA monitoring audit and 5 (4%) by the CMOs’ letter
Improvements included:

- Adding prompts or similar to EPRs/proformas
- Altering standard GP letters
- Improving advice to patients
- Conducting audit

2 services had audited the effect of change and 15 planned to do so
Conclusions

It is encouraging that:

- most services take action to advise both patients and GPs about flu vaccine eligibility
- 20% report quality improvement in the past year
Recommendation

For further improvement and ensuring coverage whether or not an HIV patient attends during the vaccine season, all services should:

- Mention flu vaccine eligibility routinely in GP letters (eg footnote in standard template)
- Include asking about flu vaccine in EPRs/proformas for annual clinician review
- Consider feasibility of reminding patients (eg by text) at start of flu vaccine season
- Consider auditing recording of flu vaccine advice to patients
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