MORTALITY AND LATE DIAGNOSIS REVIEWS – AN UPDATE
Context

2018 BHIVA standards

Providers of NHS HIV care should review deaths and serious incidents, which may include late HIV diagnoses, in accordance with current policy frameworks (Standard 4a).

Proportion of all deaths of HIV patients with documented evidence of review of the death, including those admitted to an inpatient unit (target: 95%) (Standard 8b).

Proportion of services undertaking a review of all patients diagnosed late and very late with ‘look back’ of previous engagement with healthcare services (target 95%) (Standard 1a).
Context

Targets

UNAIDS and FTCi targets of ‘getting to zero’ in relation to deaths in people living with HIV

UNAIDS: fewer than 500 000 people dying from AIDS-related causes

FTCi: zero preventable HIV-related deaths
London HIV Mortality Review 2018
Background


Annual review of deaths among people with HIV in London since 2013

Aims:

Improve quality of patient clinical and end of life care by reviewing the patient pathway of HIV patients who die in London

Identify particular scenarios that are worthy of further case investigation

Public health benefit through identifying areas to focus outcome measures to prevent people dying early

Observe and changes in CoD over time
Methods

All trusts commissioned by NHS England to provide HIV care in London were invited to report data on all patients who died in 2017 either at their centre or who attended their centre for routine HIV care.

Data were submitted using a modified Causes of Death in HIV (CoDe) on SNAP survey.

Information collected included: comorbidities, treatment, clinical markers, causes of death, missed opportunities and end of life care.

Data were submitted to PHE for cleaning and analysis.

Cause of death was classified by two clinicians using the CoDe protocol.

Assessment was made as to whether the death was preventable.
An audit of mortality among HIV patients in London

Since 2013, the London Mortality Study Group has conducted annual reviews of deaths among people with HIV with an aim to reduce avoidable mortality and improve the quality of patient care.

This online tool should be used to report information on all deaths among patients attending for HIV care at your London clinic. Any questions left incomplete at the time of submission will be defaulted to "unknown".

The deadline for submission of 2017 deaths is the 15th of October, 2018. Deaths among people with HIV in 2018 can be submitted any time; the formal submission deadline will be next year.

This form can save partial responses, to be completed at a later date. Click "Save" and bookmark the unique link that is generated. Return to this link to resume inputting information.

If you have any queries, please contact Sara Croxford (Public Health England): sara.croxford@phe.gov.uk or 020 8327 7406 or Tracy Palmer (NHS England): tracy.palmer2@nhs.net or 077 0240 9447.

Contact information

To report a death among a patient with HIV, you must supply your contact information. You may be contacted to verify your identity, clarify your responses or follow-up missing information.

Questions which are marked with an asterisk (*) are mandatory

Q1 Name of data reporter*:
Q2 Email of data reporter*:
Q3 NHS clinic of HIV care*:
Q4 NHS Trust of HIV care:
Data collected

Demographics
Risk factors
Co-morbidities
Circumstances of death (expected vs unexpected)
Cause (s) of death
Post-mortem
Missed opportunities for earlier HIV diagnosis
Clinical profile and HIV treatment
Adverse events related to any NHS intervention
Overview

Total deaths in 2017
Men 128 75%
Women (incl one trans woman) 46 25%
Age at death:

Men
- 25-34: 29%
- 35-44: 20%
- 45-54: 16%
- 55-64: 9%
- 65-74: 4%
- 75+: 4%

Women
- 25-34: 24%
- 35-44: 37%
- 45-54: 13%
- 55-64: 11%
- 65-74: 11%
- 75+: 4%
Cause of death by gender

<table>
<thead>
<tr>
<th>Category</th>
<th>Men</th>
<th>Women</th>
</tr>
</thead>
<tbody>
<tr>
<td>AIDS</td>
<td>19</td>
<td>10</td>
</tr>
<tr>
<td>Non-AIDS infections</td>
<td>20</td>
<td>8</td>
</tr>
<tr>
<td>Liver disease</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Non-AIDS cancer</td>
<td>30</td>
<td>14</td>
</tr>
<tr>
<td>CVD/stroke</td>
<td>1</td>
<td>6</td>
</tr>
<tr>
<td>Respiratory disease</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td>Accident</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Suicide</td>
<td>8</td>
<td>8</td>
</tr>
<tr>
<td>Substance misuse</td>
<td>11</td>
<td>4</td>
</tr>
<tr>
<td>Other</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>Unknown</td>
<td>15</td>
<td>5</td>
</tr>
</tbody>
</table>
Cause of death by gender

Proportions where data reported (N=154/174)

Men

Women
Clinical care - ART

95% (165/173) of patients ever on ART

Median time on treatment before death: 10 years (IQR: 7-14 years)

84% (124/147) on ART at death*

Reasons for not being on ART:

<table>
<thead>
<tr>
<th>Reasons</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>LTFU</td>
<td>6</td>
<td>26%</td>
</tr>
<tr>
<td>Non adherence</td>
<td>4</td>
<td>17%</td>
</tr>
<tr>
<td>Palliative care</td>
<td>3</td>
<td>13%</td>
</tr>
<tr>
<td>Patient choice</td>
<td>7</td>
<td>30%</td>
</tr>
</tbody>
</table>
| Reduce pill burden    | 1 | 4% | *in the year prior to death
| Unwell                | 2 | 9% |
Clinical care - biomarkers

CD4 count at death* (cells/mm³)

- <200: 18%
- 200-349: 24%
- 350-499: 39%
- ≥500: 19%

Viral load at death* (copies/ml)

- <50: 22%
- 50-199: 9%
- 200-1499: 4%
- ≥1500: 65%

*in the year prior to death
Late diagnosis and missed opportunities

14 patients died within a year of diagnosis:

- 64% (9/14) diagnosed late
- 50% (7/14) diagnosed very late
- 50% (7/14) with an AIDS-defining illness at diagnosis

Missed opportunities for earlier diagnosis:

<table>
<thead>
<tr>
<th>Setting</th>
<th>1 year prior to diagnosis</th>
<th>5 years prior to diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%</td>
</tr>
<tr>
<td>Primary care</td>
<td>7</td>
<td>23%</td>
</tr>
<tr>
<td>Sexual health service</td>
<td>2</td>
<td>6%</td>
</tr>
<tr>
<td>Accident &amp; Emergency</td>
<td>3</td>
<td>9%</td>
</tr>
<tr>
<td>Hepatitis clinic</td>
<td>1</td>
<td>4%</td>
</tr>
<tr>
<td>Neurology outpatient</td>
<td>1</td>
<td>4%</td>
</tr>
<tr>
<td>Oncology</td>
<td>1</td>
<td>4%</td>
</tr>
<tr>
<td>Substance misuse</td>
<td>0</td>
<td>0%</td>
</tr>
</tbody>
</table>
End of life care

59% (76/129) of patients had an end of life discussion

70% (38/54) had an advanced end of life care plan

57% (74/129) DNR in place

Where it was known all but 2 people died where they wanted to die

Preference for place of death

- Home: 11%
- Hospice: 18%
- Hospital: 16%
- Nursing home: 4%
- Other: 1%
- Unknown: 49%
Preventable death

18% (32) of deaths were HIV-related and preventable
- Cause of death an AIDS-defining illness
- Died within a year of diagnosis
- Diagnosed late or with AIDS at diagnosis
- Missed opportunities for earlier diagnosis
- Never on ART, not adherent or LTFUP

20% (35) of deaths were not HIV-related but preventable
- Suicide
- Substance misuse
- Smoking tobacco
Conclusions

Significant number of preventable deaths (38% of all)

- Address underlying risk factors (e.g. smoking and substance misuse)
- Promote psychological well being
- Earlier diagnosis of HIV
- Improve care engagement
Future plans

Agree definitions of ‘preventable deaths’ and zero

Collaboration between PHE and BHIVA to expand the London review – National Mortality Review
National Mortality Review

Services should include both individuals for whom they have provided HIV care and individuals dying under their care who previously attended elsewhere for HIV care

Data for 2019 deaths to be submitted before the end of March 2020

Presentations at conferences, wider annual mortality review meeting, local regional meetings

Data will be incorporated into PHE’s HIV surveillance systems, with no need to report deaths through other surveillance mechanisms

https://snapsurvey.phe.org.uk/nationalhivdeathreview
Pilot of late HIV diagnosis review process (LDRP)
LDRP pilot

David Chadwick and Ming Lee (BHIVA 2019)

Pilot of late diagnosis reviews

- Multiple sites across England and Wales
- Common database for documenting types of missed opportunities (MO), where they occurred, harm suffered etc.

Evaluation of pilot – online survey to site leads
Review Process for Previous Healthcare Episodes

Case-notes review – both inpatient/outpatient episodes; paper or electronic

Pathology system: e.g. ICE plus OpenNet function

Summary Care Record (NHS Spine) – GP prescriptions

Other electronic record systems...

Patient recall of accessing healthcare..
## Feedback process for late diagnoses

<table>
<thead>
<tr>
<th>Feedback</th>
<th>No or minimal Harm (0/1) Demonstrated</th>
<th>Some Harm (2/3) Demonstrated (‘AE’-equivalent)</th>
<th>Serious Harm (4/5) Demonstrated (SI) (‘SAE’-equivalent)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Delayed diagnosis; no clear evidence of missed opportunities for testing</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Delayed diagnosis &amp; possible missed opportunities for testing</td>
<td>Letter to relevant service</td>
<td>Letter to relevant service</td>
<td>Serious Learning Event (SLE)</td>
</tr>
<tr>
<td>Delayed diagnosis &amp; definite missed opportunities for testing</td>
<td>Letter to relevant service</td>
<td>Serious Learning Event (SLE)</td>
<td>Serious Incident (RCA)</td>
</tr>
</tbody>
</table>
# Grading of harm suffered
(adapted from NPSA)

Table 1a Assessment of the severity of the consequence of an identified risk: domains, consequence scores and examples of the score descriptors

<table>
<thead>
<tr>
<th>Domains</th>
<th>Consequence score (severity levels) and examples of descriptors</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Impact on the safety of patients, staff or public (physical/ psychological harm)</td>
<td></td>
<td>Minor injury requiring no/minimal intervention or treatment</td>
<td>Minor injury or illness requiring minor intervention</td>
<td>Moderate injury requiring professional intervention</td>
<td>Major injury leading to long-term incapacity/ disability</td>
<td>Incident leading to death</td>
</tr>
<tr>
<td></td>
<td></td>
<td>No time off work required</td>
<td>Requiring time off work for ≤3 days</td>
<td>Requiring time off work for 4–14 days</td>
<td>Requiring time off work for &gt;14 days</td>
<td>Multiple permanent injuries or irreversible health effects</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Increase in length of hospital stay by 1–3 days</td>
<td>Increase in length of hospital stay by 4–15 days</td>
<td>Increase in length of hospital stay by &gt;15 days</td>
<td>Increase in length of hospital stay by &gt;15 days</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>RIDDOR/agency reportable incident</td>
<td>An event which impacts on a small number of patients</td>
<td>Mismanagement of patient care with long-term effects</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>An event which impacts on a large number of patients</td>
</tr>
</tbody>
</table>
Results

15 Trusts participated in the LDP

Total number of late presenters in pilot period = 127

Total number of late presenting patients with missed opportunities = 40 (31.5%)

68 missed opportunities in total

No. of missed opportunities identified
No. of late presenters CD4 <200 (July 2018 – Dec 2018)
Harm to patients

Late presenters with missed opportunities were more likely to experience high levels of harm at diagnosis.

NPSA/NRLA Harm Grading

- Level 0 (No harm)
- Level 1
- Level 2
- Level 3
- Level 4
- 5 (Death)

- No missed opportunities
- Missed opportunities

p < 0.0001
Outcome of LDRP review

- **Serious Incident - Root Cause Analysis required**: 4
- **Serious Learning Event**: 8
- **Letter sent to service**: 15

2 deaths where MO occurred (SI+RCA)
Feedback to services

10 sites contacted the relevant services where missed opportunities for earlier HIV testing were identified

Statements best describing response(s) from contacted services

- They have engaged in the feedback process and have made/are planning changes to prevent future missed opportunities for earlier HIV testing.
- They have acknowledged the feedback but it is unclear if they have engaged in the review process.
- They have declined to engage in the review process.
- They have not responded to the feedback from this review process.
Missed opportunities for HIV testing still occurring in a third of very late presenters and associated with increased harm, including death.

Late presenters with missed opportunities more likely to be non-white and born outside the UK.

Feedback to other services where missed opportunities occurred is challenging, and HIV departments should liaise with patient safety teams to improve feedback cycles.

The LDRP was a sustainable process with current resources in most centres.

Adoption of late diagnosis reviews should contribute to achieving BHIVA standards of care, improving diagnosis and minimising harm to patients.
Future

CRG are supportive of LDRP becoming a commissioned standard. BHIVA will work with the CRG to produce revised materials, based on the pilot materials, to enable units to carry out the LDRP. These will include definitions (e.g. MO) and clarification that specific patient/family consent isn’t required (as it is an established patient safety procedure) nor is consent to use SCR (GP record) as part of the investigation.

Exploring minimal data collection via HARS, including whether LDRP carried out; whether any missed opportunities to test identified and if so whether SI/SLE investigation done.

The three Coroner’s cases in a single region are being reviewed by the lead Coroner, and it is likely this will result in a Regulation 28 (prevention of future deaths) notice aimed at NHS providers and other stakeholders to adhere to BHIVA/NICE testing guidelines.
Acknowledgments

London Mortality Review

All Clinicians in mortality data collection
Amanda Heeralall (NHSE)
Sebastian Lucas
Rob Miller
Frank Post
Richard Harding
Sara Croxford (PHE)

LDRP
David Chadwick
Ming Lee
Mas Chaponda
Philippa Matthews (RCGP)
Valerie Delpeche (PHE)
Ming Lee

Pilot Site Leads

Nick Labracestier, GSTT
Daniella Chilton, GSTT
Emily Clarke, RLBUHT
Emma Rutland, WSH
Yvonne Gileece, BSUH
Athavan Umapal, BHR
Clare van Helsema, PAT
Joanne Bassett, Sheffield
Karen Rogstad, Sheffield
Amy Mammen-Tobin, Leeds
Sarah Schoeman, Leeds
Iain Stephenson, Leicester
Adrian Palfreeman, Leicester

Ashley Price, NUTH
Laurence Dufour, Barts Health
Chloe Orkins, Barts Health
Andrew Freedman, Cardiff
Lucy Garvey, Imperial NHS
Iain Reeves, Homerton
Nikhil Premchand, Northumbria
Luciana Rubinstein, NWUHT
Megan Jenkins, NBT
Francesca Knapper, NBT
Mark Gompels, NBT