25th Annual Conference of the British HIV Association
Bournemouth 2019
Declarations

- Dr Ming Lee has no conflicts of interests relevant to this presentation.
Pilot results from late HIV diagnosis and review process

Dr Ming Lee
Dr David Chadwick
• In 2016 around 2,066 patients in England diagnosed late (CD4<350): late diagnoses were preventable in over 1,000 patients

• That year roughly 150 cases of AIDS were preventable and potentially 100-200 deaths were preventable if previous testing opportunities not been missed

BHIVA Standards of Care for People Living with HIV 2018

Audit outcomes for Standard 1

- Proportion of services undertaking a review of all patients diagnosed late (CD4 count <350 cells/mm³) or very late (CD4 count <200 cells/mm³ or AIDS), with 'look back' of previous engagement with healthcare services (target: 95%). This critical case review should:
  - Be in line with the forthcoming national standardised process for reviewing late diagnoses (currently in development);
  - Include provision of summary information to commissioners to aid greater understanding of interventions to reduce late diagnosis.
• Pilot of late diagnosis reviews
  • Multiple sites across England and Wales

• Evaluation of pilot – Online survey to site leads
Pilot process for reviewing late HIV diagnoses (July – December 2018)

1. CD4<200 or AIDS in new patient?
   - No → No further investigation
   - Yes → Patient been in UK > 2 months and either (i) suffered some harm (due to delayed diagnosis) or (ii) have AIDS?

2. Patient been in UK > 2 months and either (i) suffered some harm (due to delayed diagnosis) or (ii) have AIDS?
   - No → No further investigation
   - Yes → Preliminary investigations* suggests missed opportunities for testing (2/12 – 5yrs ago)

3. Preliminary investigations* suggests missed opportunities for testing (2/12 – 5yrs ago)
   - No → No further investigation
   - Yes → Clear or likely missed opportunities for testing found and definite, serious harm resulted from delayed diagnosis?

4. Clear or likely missed opportunities for testing found and definite, serious harm resulted from delayed diagnosis?
   - No → Serious Learning Event
   - Yes → SI Report with full RCA & report to PHE and commissioners

* Case-notes review – both inpatient/outpatient episodes
Pathology system: e.g. ICE plus OpenNet function
Summary Care Record (NHS Spine) – GP prescriptions
Other electronic record systems…
Patient recall of accessing healthcare..
Definition of missed opportunities

- Adapted from 2008 BHIVA testing guidelines
  - Definite missed opportunities
    - If meets criteria for clinical indicator diseases for HIV infection
  - Possible missed opportunities
    - Examples: Single episode of pneumonia, shingles, weight loss
NPSA/NRLA Harm Grading System

For this process, harm suffered to be put in 1 of 3 categories:

- **Minor (Grade 0/1)** – ‘0’ means no harm (asymptomatic)
- **Intermediate (Grade 2/3)**
- **Major (Grade 4/5)**

<table>
<thead>
<tr>
<th>Consequence score (severity levels) and examples of descriptors</th>
</tr>
</thead>
<tbody>
<tr>
<td>Domains</td>
</tr>
<tr>
<td>1 Negligible</td>
</tr>
<tr>
<td>2 Minor</td>
</tr>
<tr>
<td>3 Moderate</td>
</tr>
<tr>
<td>4 Major</td>
</tr>
<tr>
<td>5 Catastrophic</td>
</tr>
</tbody>
</table>

- **Impact on the safety of patients, staff or public (physical/psychological harm):**
  - Minimal injury requiring nonminimal intervention or treatment
  - No time off work required
  - Minor injury or illness requiring minor intervention
  - Requiring time off work for ≤3 days
  - Increase in length of hospital stay by 1–3 days
  - Moderate injury requiring professional intervention
  - Requiring time off work for 4–14 days
  - Increase in length of hospital stay by 4–15 days
  - RIDDOR/agency reportable incident
  - An event which impacts on a small number of patients
  - Major injury leading to long-term incapacity/disability
  - Requiring time off work for >14 days
  - Increase in length of hospital stay by >15 days
  - Mismanagement of patient care with long-term effects
  - Incident leading to death
  - Multiple permanent injuries or irreversible health effects
  - An event which impacts on a large number of patients
### Feedback process for late diagnoses

<table>
<thead>
<tr>
<th>Delayed diagnosis; no clear evidence of missed opportunities for testing</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><strong>Delayed diagnosis &amp; possible missed opportunities for testing</strong></td>
<td>Letter to relevant service</td>
<td>Letter to relevant service</td>
<td>Serious Learning Event (SLE)</td>
</tr>
<tr>
<td><strong>Delayed diagnosis &amp; definite missed opportunities for testing</strong></td>
<td>Letter to relevant service</td>
<td>Serious Learning Event (SLE)</td>
<td>Serious Incident (RCA)</td>
</tr>
</tbody>
</table>
Evaluation of Late Diagnosis Pilot (LDP)

- Online structured survey sent to individual site leads

- 4 domains
  - Consent process
  - RCA and SLE analysis
  - Feedback to external services
  - HIV services experience of the LDP

- Statistical analysis done in Minitab, and univariate analysis using student’s T test for continuous, and $\chi^2$ test for categorical variables
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
### Demographics

<table>
<thead>
<tr>
<th>Demographic</th>
<th>Late presenters without missed opportunities (N=87)</th>
<th>Late presenters with missed opportunities (N=40)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Mean Age</strong></td>
<td>44 years (SEM ± 1.3)</td>
<td>47 years (SEM ± 2.0)</td>
<td>NS</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
<td>NS</td>
</tr>
<tr>
<td>Male</td>
<td>60 (69.0%)</td>
<td>31 (77.5%)</td>
<td>NS</td>
</tr>
<tr>
<td>Female</td>
<td>26 (29.9%)</td>
<td>9 (22.5%)</td>
<td>NS</td>
</tr>
<tr>
<td>Transgender</td>
<td>1 (1.1%)</td>
<td>0 (0.0%)</td>
<td>NS</td>
</tr>
<tr>
<td><strong>Likely route of HIV acquisition</strong></td>
<td></td>
<td></td>
<td>NS</td>
</tr>
<tr>
<td>Heterosexual</td>
<td>60 (69.0%)</td>
<td>24 (60.0%)</td>
<td>NS</td>
</tr>
<tr>
<td>MSM</td>
<td>25 (28.7%)</td>
<td>16 (40.0%)</td>
<td>NS</td>
</tr>
<tr>
<td>Other</td>
<td>2 (2.3%)</td>
<td>0 (0.0%)</td>
<td>NS</td>
</tr>
<tr>
<td><strong>Ethnicity</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Non-White</td>
<td>46 (52.9%)</td>
<td>12 (30.0%)</td>
<td>0.016</td>
</tr>
<tr>
<td>White</td>
<td>41 (47.1%)</td>
<td>28 (70.0%)</td>
<td></td>
</tr>
<tr>
<td><strong>Country of birth</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Outside UK</td>
<td>61 (70.1%)</td>
<td>17 (42.5%)</td>
<td>0.003</td>
</tr>
<tr>
<td>UK born</td>
<td>26 (29.9%)</td>
<td>23 (57.5%)</td>
<td></td>
</tr>
</tbody>
</table>
HIV Diagnosis

- Mean CD4 counts were lower at diagnosis in late presenters with missed opportunities for earlier HIV testing

![Interval Plot of Initial CD4 (cells/ml)](image)

*Interval Plot of Initial CD4 (cells/ml) 95% CI for the Mean*

<table>
<thead>
<tr>
<th>Were there possible missed opportunities for HIV testing</th>
<th>Initial CD4 (cells/ml)</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td><img src="image" alt="Initial CD4 (cells/ml) No" /></td>
<td><img src="image" alt="Initial CD4 (cells/ml) Yes" /></td>
</tr>
</tbody>
</table>

P = 0.003

![Interval Plot of Initial HIV viral load (cpml)](image)

*Interval Plot of Initial HIV viral load (cpml) 95% CI for the Mean*

<table>
<thead>
<tr>
<th>Were there possible missed opportunities for HIV testing</th>
<th>Initial HIV viral load (cpml)</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td><img src="image" alt="Initial HIV viral load (cpml) No" /></td>
<td><img src="image" alt="Initial HIV viral load (cpml) Yes" /></td>
</tr>
</tbody>
</table>

P = 0.616

- AIDS-defining illnesses were also more common (65.0% vs 35.0%, p=0.001)
Harm to patients

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

NPSA/NRLA Harm Grading

<table>
<thead>
<tr>
<th>Level</th>
<th>No missed opportunities</th>
<th>Missed opportunities</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 (No harm)</td>
<td>30%</td>
<td>26%</td>
</tr>
<tr>
<td>1</td>
<td>13%</td>
<td>15%</td>
</tr>
<tr>
<td>2</td>
<td>6%</td>
<td>18%</td>
</tr>
<tr>
<td>3</td>
<td>15%</td>
<td>28%</td>
</tr>
<tr>
<td>4</td>
<td>15%</td>
<td>5%</td>
</tr>
<tr>
<td>5 (Death)</td>
<td></td>
<td>1%</td>
</tr>
</tbody>
</table>

P < 0.0001
Outcome of LDP review

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

- 3 coroners cases – inquests pending – outside BHIVA pilot period
  1. Coroner’s inquest underway: delayed diagnosis with multiple missed opportunities at medical outpatient appointments (oral candidiasis, lung nodules, weight loss)
  2. Coroner’s referral made: death from AIDS-defining condition on background treatment with biologics for inflammatory bowel disease, not tested
- Through use of governance systems and coroners referrals, proposed task and finish group set up to establish universal testing.
Evaluation of LDP – Survey results

- Responses from 12 sites

- LDP was carried out either with presumed consent (50%) or verbal consent sought (50%)

- Reasons for not being able to carry out LDP

<table>
<thead>
<tr>
<th>Reason</th>
</tr>
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<tbody>
<tr>
<td>Access to SCR/Spine was not available during audit period</td>
</tr>
<tr>
<td>Patient died before consent could be obtained</td>
</tr>
<tr>
<td>We were unable to contact one patient during the study period to obtain consent</td>
</tr>
<tr>
<td>1 patient was not approached as it was felt that this would be distressing due to their severe mental health problems</td>
</tr>
</tbody>
</table>

- All other patients contacted gave consent for LDP
RCA and SLE analysis

What happened in the case(s) which satisfied the criteria for SLE/RCA review

- An alternative patient safety improvement process took place not requiring an incident report
- SLE/RCA was initiated but an incident report (eg DATIX) has not yet been logged
- SLE/RCA was initiated and an incident report (eg DATIX) was logged

1. Incident report will be logged by the relevant service
2. Not related to our trust
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.
Individual HIV services’ experience of LDP

Which member(s) of the multidisciplinary team were involved in the process of identifying missed opportunities for earlier testing in late diagnosis:
- Clinicians
- Specialist nurses
- Health advisors
- Administrative staff
- Others

How many hours a week on average has this review required in your department for the staff member(s) involved in this review process:
- Less than an hour
- 1 – 2 hours a week
- 2 – 4 hours a week

Is this a sustainable process in your department:
- Yes
- No
Individual sites’ experience of LDP

Very much in favour of the process, although in the single case we identified in the pilot, it was uncertain whether there were clearcut missed opportunities in the GP setting.

Our service has undertaken a HIV late diagnosis review which is discussed alongside our Mortality meeting every year. At our last review, feedback was sought from GPS regarding the type of feedback they would find most helpful. Feedback options include:

1. A general ‘lessons learned’ letter to all GP surgeries (Leeds, Wakefield and Dewsbury) including the results of our audit and describing HIV clinical indicator scenarios with potential opportunities for early HIV testing
2. A letter regarding the specific patient from your practice with further information
3. Training sessions on HIV testing and clinical indicator conditions
4. All of the above

Hard to do this prospectively patients were bought to HIV MDT

Datix and initiating RCA’s is less time consuming than chasing external organisations for patient care reviews. We can’t do the latter with current time available. We sent 2 requests for RCA’s external but they haven’t as far as we are aware done them as they did not recognise missed opportunities.

Useful if we could have had access to GP systems
Summary

- Patients with lower CD4 count, AIDS-defining illness and increased harm at diagnosis, including death are still more likely to have missed opportunities for earlier HIV testing.

- Caucasian ethnicities and those born in the UK more likely to have missed opportunities for earlier testing.

- Some Trusts’ Patient Safety Teams were cautious about or reluctant to use SI/SLE processes.
Summary

- Process of obtaining consent for accessing records varied during the pilot, and should consider undertaking review of late diagnoses in the interest of patient safety, informing patients where possible.

- The LDP was a sustainable process with current resources in most centres

- Adopting late diagnoses review can lead to improvements in patient safety and preventing further missed opportunities e.g. Manchester example

- Next steps – UK-wide process
Acknowledgements

Pilot Site Leads
- Nick Larbalestier, GSTT
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- Clare van Halsema, 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

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