BHIVA Audit and Standards Subcommittee & NHS England HIV Clinical Reference Group: A proposed national process for investigating late diagnoses and potential missed opportunities for HIV testing (Revised version April 2021)

Background

People living with HIV (PLWH) continue to present to clinical services late but a significant proportion are diagnosed late because they were not tested for HIV. This includes those presenting with indicator conditions or other risk factors which should prompt testing. Late diagnosis of HIV (CD4<350) occurs in around 40% of all the 4,000 – 5,000 patients presenting each year and often has a major impact on the individual, risking clinical deterioration, and opportunistic infections.

The HIV Commission report highlights the impacts of late diagnoses, including an 8-fold increase in the risk of premature mortality, reduced response to HIV treatment in comparison with those diagnosed earlier in the course of infection and higher costs of care – direct medical costs in the first year after diagnosis are twice as high for late diagnosed individuals, largely due to higher inpatient costs. Late diagnosis represents a missed opportunity to initiate treatment, prevent onward transmission of HIV, improve the outcomes for individuals and reduce costs.

While various initiatives have attempted to promote wider uptake of HIV testing, rates of late diagnosis remain stubbornly high in certain areas of the UK and amongst particular subgroups, especially those from ethnic minorities and heterosexual men and women. A recent BHIVA Audit (2016) identified nearly half of all PLWH presenting late as having had clear missed opportunities for testing, with 71% of all patients having attended primary or secondary care in the 2 years prior to diagnosis. It also showed that only 55% of units had a formal process for reviewing late diagnoses and methods to review late diagnosis varied across units and around the UK; late diagnosis was rarely seen because the patient had recently arrived in the UK with few or no opportunities for testing.

Both BHIVA and the HIV Clinical Reference Group (CRG) have recommended that services conduct reviews of late diagnosis and HIV-related deaths for several years, although no standardised method for reviews has been proposed. Moreover when these reviews occur different units use a variety of data sources and conduct the reviews in different ways. There are no standardised actions plans resulting from such reviews and reporting the results of reviews or lessons learnt to commissioners is irregular or frequently absent, even when deaths are likely to have resulted from missed opportunities for HIV testing. Anecdotally, deaths associated with late HIV diagnoses and clear missed opportunities for testing are seldom referred to a Coroner. For a few years the South West region did undertake root cause analyses (RCAs) with serious incident (SI) reporting for very late diagnoses, however this process appears to have been arduous and perhaps not ideal for all late diagnoses.

In a substantial proportion of late diagnoses missed opportunities for testing have occurred and patients often suffer substantial harm or death as a result of late diagnosis. There is therefore a strong case for developing a more robust and nationally applicable review process, to identify and learn from possible earlier missed opportunities for testing.

Aims of process

The goal of this work is to contribute toward the zero transmissions by 2030 ambition for the UK, by reducing the proportion of people newly diagnosed with HIV who receive a late diagnosis. This goal is underpinned by the following 4 aims:

1. To encourage HIV clinicians, via a CRG-commissioned standard, to grade and report all late diagnoses (AIDS diagnosis at any CD4 count, CD4<350) according to whether missed opportunities for testing were likely and what level of harm may have occurred, via a standardised review process.
2. To support HIV services to feedback directly to clinicians regarding missed opportunities for testing and as an opportunity to encourage reflection and learning in clinical areas where testing practice can be improved.
3. To support PHE to use data from late diagnosis reviews to expand national and regional HIV reports to identify the demographics of people receiving late diagnoses who do and do not have missed opportunities, and to identify locations of and reasons for missed opportunities.
4. To enable public health teams supporting local health and care systems to identify barriers to broader HIV testing and take advantage of opportunities to strengthen routine HIV testing in a variety of settings and across all groups within the population.

LDRP methodology

(1) Identify cases – all new late diagnoses of HIV (CD4<350 and/or AIDS) aged 18 or over[1] should be reviewed within 2 weeks of presentation

(2) Set up an individual case record for each case – insert baseline demographic and other data available from HIV service records individual case records

(3) Contact the case to inform them about the review – use this opportunity to collect information from patient recall about healthcare attendances from 2 months to 5 years prior to diagnosis

(4) Identify other sources of information – this could include laboratory records or secondary care records where available to the service

(5) Contact other healthcare providers relevant to the case – this is likely to include the GP but may also include sexual health service(s) and secondary care provider(s)

(6) Review information returned to identify missed opportunities (MO) for testing – record in the individual case record noting whether each MO was either:

   a. Probable/definite – where there is clear evidence of a criteria for testing being noted during the episode (e.g. diagnosis of a clinical indicator for HIV) and no test being offered; or

   b. Possible – where there is a strong clinical rationale for testing in the absence of a probable/definite characteristic

[1] excluding patients with a positive RITA suggesting recent infection, a negative HIV test in the previous 2 years or who were resident in UK for less than 2 months prior to diagnosis

(7) Conduct any local actions considered appropriate in response to MO – this could involve writing to the relevant clinician or service, for example, or undertaking a multidisciplinary team review as a learning opportunity; also note whether a patient safety incident has been declared

(8) Transfer the individual case record summary into a local database – this will make the data ready for upload

(9) Write to the patient (or next of kin, where appropriate) – include a summary of your investigation, key findings and actions that have been taken as a result (Duty of Candour)

(10) Submit findings – at least annually, upload findings from late diagnoses reviews to the national late diagnosis review snap survey tool

Important points

- Ownership: while reviews will need to be overseen by an experienced HIV clinician, services should partner with patient safety teams to ensure these reviews are appropriately governed and feed into the organisation's overall patient safety plan
- Consent: ideally PLWH or next of kin's consent should be sought for the review process as this is likely to involve accessing information outside of the HIV service organisation, either through electronic systems or by requesting such information from partner organisations; however if this is not possible, clinicians should still seek such information without consent in the interests of patient safety reporting
- Information governance (IG): data collected for reviews will necessarily include patient identifiers and is highly sensitive. Where sharing outside the organisation all care should be taken to ensure security, for example, using NHS.net to NHS.net emails and/or removing identifiers. Internally, all care should be taken to store the data securely and with access limited to those who require access to support the LDRP process. Processes should comply with local IG arrangements and the General Data Protection Regulations (GDPR).
- Deaths due to missed opportunities: if the PLWH died, missed opportunities to test are identified, and the HIV clinician's view is that the death was likely preventable had the diagnosis been made earlier, the reviewing clinician (if not looking after the PLWH) should advise the medical team to report the death to the Coroner, or could report the death themselves. This should occur even if a death certificate has already been issued. The HIV clinician or medical team should indicate to the Coroner which clinical service (e.g. hospital clinic/GP surgery) had missed an opportunity to test the patient and when it occurred. In most cases the Coroner will conduct an inquest, although a post-mortem may not always be needed as the cause of death is often clear. Teams are also encouraged to enter details of deaths into the online national mortality questionnaire.[2]
- Grading of harm: the national patient safety framework is currently under revision. To ensure consistency of definition, the LDRP uses the definitions of harm from the original National Patient Safety Agency's seven steps to patient safety (2004)[3] document:

[2] Website reference: https://snapsurvey.phe.org.uk/nationalhivmortalityreview

[3] https://webarchive.nationalarchives.gov.uk/20150505145833/http://www.nrls.npsa.nhs.uk/resources/collections/seven-steps-to-patient-safety/?entryid45=59787

Term	Definition
No harm	Any patient safety incident that did not result in harm or injury or had the potential to cause harm but was prevented, resulting in no harm (near miss)
Low harm	Any patient safety incident needing extra observation or minor treatment
Moderate harm	Any patient safety incident resulting in a moderate increase in treatment. The incident caused significant but not permanent harm.
Severe harm	Any patient safety incident that appears to have resulted in permanent harm.
Death	Any patient safety incident that directly resulted in death

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