Public Health England

BHIVA British HIV Association

Late HIV Diagnosis Review

Thank you for taking the time to respond to this Late Diagnosis Review Protocol (LDRP).

This online tool should be used to report information on late HIV diagnosis review outcomes among patients attending for HIV care at your clinic. More information on how to conduct a late HIV diagnosis review can be found here.

Through this data collection we are aiming to gather information about the missed opportunities that may have contributed to failures in the prompt diagnosis of HIV. We know that late diagnosis has a significant impact on people living with HIV. It can increase mortality, worsen morbidity and result in higher treatment costs. The LDRP has been developed by the British HIV Association (BHIVA) to support services to meet the standard for auditing all late diagnoses. By looking at the full picture of what may have occurred in the run up to late diagnoses, we can seek to make systemic changes that could promote earlier identification and testing, improving outcomes for people living with HIV and minimising the risk of unwitting transmission to others.

The full LDRP is currently being trialled in the PHE South East region – we welcome all and any comments regarding the content and format of the survey to ensure it is easy to complete and produces useful information for action. We are aiming to produce a regional and upper-tier local authority report identifying key themes about, and recommendations to address, late diagnoses.

This form is the short version currently available to services outside of the PHE South East Region. This survey allows you to record high level information about late diagnosis reviews you have conducted without asking for detailed information about the process and characteristics of missed opportunities identified. If the pilot in the South East is successful, the long form survey will be made available to all services.

Patient Eligibility

To be eligible for this survey the patient must meet ALL of the following criteria:

The patient has CD4 count of <350 cells/ul or a diagnosis of AIDS.

No evidence of recently acquired HIV (e.g. positive RITA or negative HIV test within the past 2 years).

The patient has been in the UK for 2 months or longer prior to diagnosis.

Please confirm that this is the case

- ◯ Yes
- ◯ No

This survey aims to collect the findings of an investigation into likely missed opportunities for HIV testing between 2 months and 5 years prior to diagnosis.

Please confirm that you have conducted this review.

- ◯ Yes
- ◯ No

Contact information

To report a late HIV diagnosis review outcome, you must supply your contact information. You may be contacted to verify your identify, clarify your responses and follow up missing information.

Questions in red and marked with an asterisk(*) are mandatory.

Please contact lucy.lynch@phe.gov.uk with any questions or concerns you may have.

Name of data reporter*:

Email of data reporter*:

HARS clinic code or name of NHS clinic of care*:

NHS Trust of HIV care*:

Patient identifiers

In this section please provide demographic details of the patient. These data are psuedo-anonymised to maintain patient confidentiality, with soundex code collected instead of surnames.

Soundex coding uses a set of eight rules to convert the surname into its first letter followed by three digits. It's use protects patients' confidentiality as no code is unique to particular surname, but when used with the date of birth and sex, likely duplicate reports can readily be recognised. Please use the following link to create a soundex code: https://www.ucl.ac.uk/nshpc/soundex

** Required*

Patient's soundex code of surname (e.g. A123)*

Patient date of birth (e.g. DD/MM/YYYY)*

Patient gender*

- ○ Male
- ○ Female
- ○ Non-binary
- ○ Other
- ○ Not stated (person asked but declined to provide a response)
- ○ Not known

If other please give details:

Is the patient's gender identity the same as the gender they were given at birth?*

- ○ Yes
- ○ No
- ○ Not stated (person asked but declined to provide a response)
- ○ Not known (not asked)

Patient clinic ID/Hospital number*

Patient demographics

What is the patient's ethnicity?

--Click Here--

- White
- Black African
- Black Caribean
- Black Other
- Asian
- Other/mixed
- Unknown

What if any risk factors for HIV does the patient have?

Tick all that apply

- [ ] Heterosexual
- [ ] IVDU
- [ ] MSM
- [ ] Pregnancy
- [ ] Other
- [ ] Not known

If other please specify:

HIV diagnosis details

Please provide clinical details of the patient's HIV diagnosis.

On what date was the HIV diagnosis made? (e.g. DD/MM/YYYY)*

Baseline CD4 count result (cells/ul)

Date of baseline CD4 count? (e.g. DD/MM/YYYY)

Review process outcome

Please provide details of the outcome of your review process.

Has the patient suffered any harm as a result of delayed diagnosis?*

- ◯ Yes
- ◯ No

By harm we mean impact on the safety of patients (as per NPSA/NRLA). Please refer to the protocol for more information.

What level of harm has occurred as a result of the late diagnosis? Please see below table for guidance on how to classify.

- ◯ Low harm
- ◯ Moderate harm
- ◯ Severe harm
- ◯ Death

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

Did the review identify 1 or more likely missed opportunities to test between 2 months and 5 years prior to diagnosis?*

- ◯ Yes
- ◯ No

Were any of the following actions taken?*

- ◯ Letter or other communication to team where missed opportunities occured
- ◯ Patient safety incident declared
- ◯ Other

If other, please specify: