British HIV Association: Recording and investigation of late HIV diagnoses: good practice position statement

Background and rationale

This paper provides advice to improve clinical practice with the aim of diagnosing HIV infection at the earliest possible opportunity. Often people with HIV infection present to clinical services but remain undiagnosed because they are not offered an HIV test, including those presenting with indicator conditions which should prompt testing[1]. This requires improvement because[2]:

> Late diagnosis of HIV can have a major impact on the individual, risking clinical deterioration, and opportunistic illness. Mortality within a year of HIV diagnosis is ten times higher for late-diagnosed individuals than those diagnosed promptly.
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> Individuals who present late show a reduced response to HIV treatment, in comparison with those diagnosed earlier in the course of infection.
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> Late diagnosis represents a missed opportunity to initiate treatment which prevents onward transmission of HIV, as well as benefitting the individual him or herself.
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> Costs of care are significantly higher for individuals diagnosed late. Direct medical costs in the first year after HIV diagnosis are twice as much for late diagnosed individuals, largely due to higher inpatient costs.
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> Although not well quantified, late diagnosis of HIV is also likely to be associated with avoidable costs of care *before* the diagnosis is made. This is because individuals may respond poorly to treatment for other conditions and/or undergo unnecessary investigations if HIV is not recognised as an underlying factor contributing to their presenting condition.

While various initiatives are under way to promote wider uptake of HIV testing, this guidance focuses on reviewing the previous history of contact with health services of individuals who are diagnosed late, to identify and learn from possible earlier missed opportunities for offering the HIV test. According to standards (Annex 1) all HIV clinical services should investigate late diagnosis and this position statement suggests good practice for doing so.

Conducting a review

Planning and engagement

Ideally, all local stakeholders should be involved in planning the review process, including primary and secondary care and commissioners and patient representatives. However, if wider engagement

[1] For list of indicator conditions see: British HIV Association, British Association for Sexual Health and HIV, British Infection Society: *UK National Guidelines for HIV Testing 2008*.

[2] For further evidence for the benefits of prompt HIV diagnosis and cost-effectiveness of testing, see: Health Protection Agency. *Evidence and resources to commission expanded HIV testing in priority medical services in high prevalence areas*, 2012.

proves difficult, HIV services may initiate a review themselves. As far as possible, the review method should be designed to yield systematic, quantitative data on pre-diagnosis morbidity, health service use and, if feasible, costs. Aims might include:

- Identifying specialties or settings in which HIV diagnoses are most commonly overlooked, so as to direct learning and improvement to where it will have the greatest impact.
- Identifying clinical presentations most often associated with unrecognised HIV infection, with a view to developing local testing guidelines and protocols.
- Quantifying avoidable morbidity and estimating costs as a means of bringing influence to bear on policy makers including trust boards and commissioners. In addition to direct medical care costs (and thus potentially avoidable), this may also include secondary costs related to the impact of morbidity on individuals concerned, eg time off work, loss of income and tax, need for social care and/or benefits.
- Telling stories or picking out dramatic cases, eg individuals with the highest numbers of care episodes, to create impact and momentum for improvement.

One caveat is that reviewing previous healthcare use among individuals diagnosed late with HIV provides only descriptive information, as there is no control group data on episodes of care among people without a late HIV diagnosis.

Which patients should be reviewed?

The highest priority is:

- Very late diagnoses, ie individuals with a CD4 under 200 cells/mm^3 or AIDS-defining condition at HIV diagnosis.

If resources permit, also include:

- Other individuals diagnosed late with a CD4 count between 200 and 350 cells/mm^3 at diagnosis.
- Individuals experiencing significant harm eg severe pneumonia admission, lymphoma diagnosis subsequent to HIV diagnosis.

Collecting data

There are two main approaches for collecting data about previous healthcare contacts among newly diagnosed HIV patients:

- Retrospective review of healthcare records. Annex 2 illustrates various ways this has been approached in practice.
- Patient-reported history recorded soon after HIV diagnosis. Annex 3 provides a suggested aide memoire for this purpose.

Data should be reviewed at least annually, if resources permit.

Improving clinical practice

Review should focus on improving clinical care through learning without blame, enabling and convincing healthcare professionals to change their practice. This process of review should include clear agreement as to whom data and results from the review will be shared with, and how it is expected this will improve clinical practice. At a local level, levers for change include:

- Discussion with clinical colleagues, informally or in grand rounds and similar settings
- Feeding information up and out through clinical senates
- Incorporation within general practice training, junior doctor induction
- Creation of a business case using potential avoidable cost and income from new diagnoses activity to make the case for routine testing in various settings
- Introduction of prompts on IT systems
- Working with commissioners to include HIV testing in contracts and in protocols/pathways for relevant services and conditions
- Formal critical or serious untoward incident reporting – while not necessarily appropriate in every instance, this ensures consideration at governance level leading to a strategic response, and enables root cause analysis.

At a national level there may be scope to influence non-HIV specialist societies and similar professional bodies to incorporate HIV testing within their own guidelines.

Although a no-blame approach should be emphasised, it should be acknowledged that review may reveal that individuals have suffered avoidable harm through not being offered a timely HIV test. This has implications especially in terms of a duty of due candour.

Annex 1: Relevant standards

BHIVA *Standards of Care for People Living with HIV 2013* states in relation to standard 1:

> 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.

Health Improvement Scotland *Human Immunodeficiency Virus (HIV) Services Standards* (2011) specifies the following quality statement in relation to standard 7:

> A critical case review is conducted for all newly diagnosed patients presenting with advanced HIV, with a mechanism established to routinely provide constructive feedback to clinical areas considered to have missed important earlier diagnostic opportunities.

Annex 2: Case studies

The following examples are not exhaustive but illustrate different approaches to obtaining information about previous healthcare contacts for individuals with HIV.

Acute trust setting: Chelsea and Westminster, Croydon

For HIV services in an acute hospital setting it is feasible to review records for an individual newly diagnosed with HIV to identify previous contact in all or selected specialties and settings across the trust:

> Chelsea and Westminster NHS Foundation Trust used hospital numbers to search Trust records for all new HIV patients between publication of the testing guidelines in 2008 and individual date of presentation, finding a total of about 17,000 episodes of care. Individuals whose first recorded viral load at the trust was <40 copies/ml were excluded on the assumption (to be checked via record sampling) that these were inward transfers rather than new diagnoses. At the time of writing more detailed review had identified 99 cases of avoidable late diagnosis, some with over 20 prior episodes of care.
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> Croydon Health Services NHS Trust reviewed records of all individuals diagnosed with HIV as inpatients during 2005-2010, and estimated cost savings that would have resulted had the diagnosis been made at initial admission. Evidence from this review formed the basis of a business case for introducing routine opt-out HIV testing in the acute medical unit[1].

A limitation of this approach is that it excludes contacts in primary care and in secondary care providers other than the trust involved. An advantage is the ability to assign costs. Even if patient-level financial data is unavailable, this may be approximated using standard categories (eg simple vs complex outpatient).

NHS data spine: Newcastle and North East

Newcastle upon Tyne Hospitals NHS Foundation Trust undertook root cause analysis for individuals diagnosed late with a CD4 count under 350 cells/mm^3. In addition to reviewing internal Trust records, the NHS data spine[2] was accessed using the patient's NHS number to identify previous episodes of care in primary care and other hospital settings across the North East. The relevant services were then asked to review their records and complete a pro-forma seeking clinical details including possible HIV indicator conditions and other earlier opportunities for testing. This was supported by work with general practices in the North East to emphasise a constructive, learning-based approach. While tracking of care episodes across multiple providers was time-consuming, this work has been well-received and has encouraged indicator-based testing in some general practices. Over 95% of individuals were found to have records on the spine of healthcare contacts within the North East.

Region-wide approach: NHS Lothian, South West England

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[1] Phillips D, Barbour A, Stevenson J, Draper S, Motazed R, Elgalib A. Implementation of a Routine HIV Testing Policy in an Acute Medical Setting in a UK General Hospital: A Cross-sectional Study. Sex Transm Infect. 2014;90(3):185-187. http://www.medscape.com/viewarticle/824389

[2] http://systems.hscic.gov.uk/spine

NHS Lothian has developed two templates for reviewing healthcare contacts in secondary and in primary care during the 24 months preceding diagnosis. The information requested includes: demographic data; HIV exposure category; place and date of diagnosis (secondary care template); healthcare contact history including locations and specialties; HIV indicator conditions/symptoms or other issues relevant to HIV; whether HIV risk status had been recorded (GP); previous history of HIV testing or barriers to this (GP). The GP template also asks whether the practice would consider undertaking a significant event analysis (SEA) and offers assistance with this.

The process for obtaining and linking data was discussed and agreed with the Local Medical (ie GP) Committee before implementation and is initiated at the Regional Infectious Diseases Unit where the data manager identifies all individuals diagnosed late with a CD4 count of <350 cells/mm^3. The secondary care template is then sent to the consultant in charge of the patient for completion using case notes, while the primary care template is sent to the patient's GP with a covering letter explaining the process and its importance. The letter stresses that GP details are kept confidential and that the purpose is to identify learning opportunities and patterns in presentation rather than to attribute blame. The completed templates are returned to the public health service for analysis, identified only by the patient's CHI number[1]. This allows for matching while maintaining confidentiality, since the public health service cannot access other personal data. The procedure is considered to be quality improvement activity not requiring explicit patient consent.

Completed templates are returned to NHS Lothian, following which data from primary and secondary care are matched together and the information is reviewed. If a GP is planning a SEA he or she is contacted again, with an offer of specialist input and education. Quarterly summary reports are provided to NHS Lothian HIV Care and Treatment Group meetings as well as feedback to clinical teams where appropriate.

A review of the process found it acceptable to clinicians, with all consultants caring for the first 18 patients completing the template together with GPs for 13 of the 15 individuals for whom GP contact was possible. Case by case review indicated that 13 individuals had had health service contact in the 24 months preceding diagnosis (including one who had declined an offer of testing), while 5 had not. The number of GP attendances during this period ranged from 1 to 22.

The South West England Office for Sexual Health engaged with primary care trusts, provider trusts and GPs to implement root cause analysis of all cases where individuals were diagnosed with HIV at a CD4 count below 200 cells/mm^3. Clinical incident reporting tools were developed, to identify circumstances of diagnosis, possible earlier opportunities for testing, consequences of late diagnosis, and clinical contacts and investigations prior to diagnosis. A strength of this initiative was community-wide agreement on a no-blame approach in which learning would be apportioned according to where the incident took place.

[1] Scottish Community Health Index number, similar to English NHS number.

Annex 3: Aide memoire for data collection with the patient

If the review is to be conducted via patient-reported data, this can be incorporated into routine history-taking for recently diagnosed individuals, since the information is clinically relevant. Its completeness will depend in part on the patient's recall, so it is a good idea to prompt at a second consultation for additional information s/he may have remembered after the initial history taking.

It is suggested that the following aide memoire could be incorporated into local protocols or checksheets for history taking with newly diagnosed HIV patients:

All prescribed medications at time of diagnosis: where and when prescribed – as well as recording for clinical purposes, use as a prompt to enquire about care received elsewhere.

Detailed *one* year history prior to HIV diagnosis:

Numbers of attendances and reasons for these in GP, OP and IP specialties (state which) and any other clinical settings

Whether HIV testing was offered – note previous negative results or declined offers of testing.

General history over *five* years prior to HIV diagnosis:

Approximate number of GP attendances

Any significant illnesses - probe for possible indicator conditions

Ask specifically about possible seroconversion-like illness (flu-like symptoms, rash, sore throat etc) – if reported note approximate date, and ask whether the patient sought clinical care and if so where, and whether an HIV test was offered.

If symptoms/illnesses/attendances reported, what impact did these have on the person's life (eg time off work)?

Has person ever had previous negative HIV test? If yes, where and when was the most recent occasion?

Has person ever declined an offer of an HIV test? If yes, where and when?

In high prevalence areas, men undergoing a blood test should routinely be offered HIV testing – hence, in high prevalence areas, if patient is male, has he had a blood test, for any reason, within the five years preceding HIV diagnosis? If yes, when and where.

For review purposes, the above information can be supplemented by background data from notes, including:

ID and demographic information: Hospital/clinic number; sex; DOB; ethnicity; HIV exposure risk.

Where diagnosed, eg: GP, home sampling, outpatient clinic (state specialty), inpatient (state specialty), other.

Whether HIV status disclosed to GP.

Clinical status at diagnosis: initial CD4, initial VL, indicator conditions present (note whether AIDS-defining), symptoms.

Annex 4: Authorship

This position statement was prepared by the BHIVA Audit and Standards Sub-Committee's Working Group on Late Diagnoses:

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