

BHIVA Audit and Standards Subcommittee

Chair: (to November 2013)

Dr ELC Ong
Newcastle General Hospital

Chair: (from November 2013)

Dr AR Freedman
University Hospital of Wales,
Cardiff

Vice Chair:

Dr SG Edwards
Mortimer Market Centre,
London

Audit Co-ordinator:

Hilary Curtis PhD

Subcommittee members:

Prof J Anderson
Homerton University Hospital,
London

Dr S Bhagani
Royal Free Hospital, London

Dr A Brown
Public Health England

Dr F Burns
Mortimer Market Centre,
London

Dr D Churchill
Royal Sussex County Hospital,
Brighton

Dr K Clay
Birmingham Heartlands Hospital

Dr V Delpech
Public Health England

Dr M Desai
St Thomas' Hospital, London

Dr PC Gupta
Diana, Princess of Wales
Hospital, Grimsby

Dr V Harindra
St Mary's Hospital, Portsmouth

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Key audit findings and recommendations

This year's main audit investigated why some people known to have HIV are not reported as receiving care. Previous studies have suggested that around 5% of people with HIV are "lost to follow-up" from one year to the next. BHIVA collaborated with clinical services and Public Health England to get a better understanding of this:

- Only 1.1% of all adults who had been diagnosed or seen for HIV care during 2010 were thought to have gone on living in the UK without attending for care in 2011
- For 1.5%, the outcome was unknown – some of these may also have remained in the UK without attending for care in 2011
- 1.4% probably left the UK
- 1.2% probably did receive care in 2011 although incomplete reporting and data matching initially suggested loss to follow-up.

Despite uncertainties, this provides reassuring evidence of excellent retention in care among people living with HIV in the UK. However, there was a high risk of disease progression among those who did not attend for care – 12% became sick and needed care in 2012, with nine inpatient admissions and seven AIDS-defining illnesses among 230 people. Non-attendance for care may also be associated with onward HIV transmission. Hence it remains essential to encourage regular attendance.

HIV clinics tried to contact 79.6% of patients who were thought to be living in the UK but not attending for care. But clinics often did not involve the patient's GP even when the latter was aware of the HIV diagnosis.

Recommendations:

- HIV services should monitor attendance and seek to re-engage patients when necessary. This should include liaising with general practice and checking patient details via national personal demographics services.
- Public health agencies should support this by providing services with annual lists of patients reported one year but not in the following year.

Separately, a survey found that only 39% of relevant BHIVA members were confident of being ready for the new English HIV AIDS Reporting System.

People with HIV who are not in care

BHIVA collaborated with Public Health England (then the Health Protection Agency) and clinical services to review the records of adults included in 2010 surveillance reporting of new HIV diagnoses ($n=6298$) and attendance for specialist HIV care ($n=64,975$) in England, Wales or Northern Ireland. Public Health England was unable to identify a matched report of care received in 2011 for 3452 of these. Clinics completed a case-note audit of 2197 (63.6%) of this group. Surveillance report matching was not undertaken in Scotland but clinics there audited a further 58 patients whom they had

seen for care in 2010 but not in 2011. This gave an audit sample of 2255 patients provisionally identified as lost to follow-up from 2010 to 2011. A sub-study sought more detailed information for five or ten patients per service depending on case load. Outcomes for the audited patients, based on clinic review of case notes, were as shown in the figure. Only 20.2% of those provisionally identified as lost to follow-up were confirmed as likely to have been living in the UK during 2011 without attending for care. For 27.8% the outcome was unknown and some of these

continued over

may also have remained in the UK without attending for care. The remainder were accounted for by having left the UK (26.2%), incomplete reporting and/or data matching among patients who probably did attend for care (22.6%), and deaths (3.2% – these were in addition to deaths already identified by Public Health England via linkage with Office of National Statistics records). These figures can be scaled up to the whole population of adults seen for HIV care during 2010:

- 1.1% thought to have gone on living in the UK without attending for care in 2011
- 1.5% outcome unknown
- 1.4% probably left the UK
- 1.2% probably did receive care in 2011 although incomplete reporting and data matching initially suggested loss to follow-up
- 0.2% deaths not initially identified via record linkage.

This suggests excellent retention in care among people living with HIV in the UK. In univariate analysis, patients who were younger, more recently diagnosed, Black African and not on anti-retroviral treatment were at greater risk of disengaging from care.

Based on sub-study data, clinical services attempted to contact 183 (79.6%) of 230 patients who remained in the UK without attending for care in 2011. However, clinics contacted the GP in only 69 (30%) of these cases, even though the GP was aware of the HIV diagnosis for 124 (53.9%).

Of 456 patients who remained in the UK without attending for care in 2011, 237 (52.0%) did attend in 2012. In the sub-study, 28 (12.2%) of 230 patients were symptomatic when they re-attended, nine were admitted as inpatients and seven developed AIDS-defining illness. This illustrates the high risk of disease progression associated with being out of care.

Although not designed for this purpose, the audit also suggested that “health tourism” for HIV care is rare. Of 195 sub-study patients who left the UK, the vast majority were previous long-term residents: 32 (16%) were UK born, 116 (60%) had arrived before the end of 2008, 22 (11%) in 2009, and 25 (13%) in 2010. A few visitors received short term care for acute illness, but not ongoing anti-retroviral treatment.

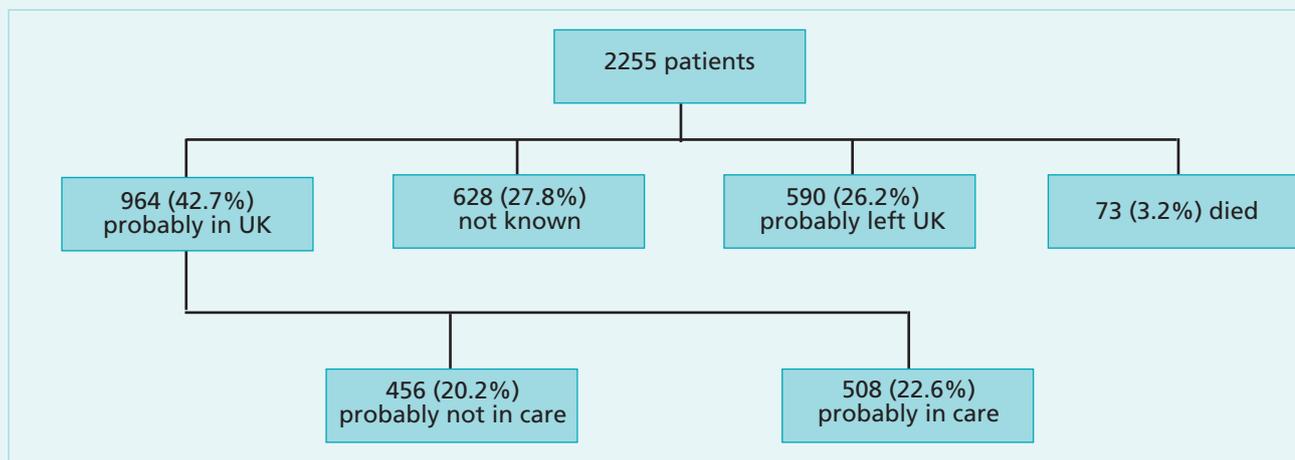


Figure: Audit outcomes for patients diagnosed or seen for care in 2010 who lacked a matched care report for 2011.

Ongoing and future BHIVA audits

BHIVA is collaborating with the British Association for Sexual Health and HIV on a joint audit of partner notification for patients with newly diagnosed HIV infection. Data collection was completed during the first half of 2013, and results will be presented in a future report.

An audit of pregnancies among women living with HIV is being planned for 2014. This will be conducted using data that are routinely collected for the National Study of HIV in Pregnancy in Childhood. Clinical sites will be asked to complete a survey but will not need to submit patient-level data for the audit.

National Clinical Audit and Patient Outcomes Programme

The National Clinical Audit and Patient Outcomes Programme (NCAPOP) is a set of centrally funded national audit projects that measure patient outcomes and provide local trusts with benchmarked reports. NCAPOP is steered by the National Clinical Audit Advisory Group (NCAAG) and procured by the Healthcare Quality Improvement Partnership (HQIP) on behalf of the Department of Health.

In September 2013 HQIP hosted a specification

development meeting for a new NCAPOP audit covering sexually transmitted infections and HIV, based on a proposal submitted jointly by BHIVA and the British Association for Sexual Health and HIV (BASHH) with the Medical Foundation for AIDS and Sexual Health (MedFASH). Following this it is expected that HQIP will publish a specification for this STI/HIV audit programme and initiate a formal procurement process for its delivery.

Audit publications

Publication and feedback is an essential part of the audit cycle, to enable clinicians and others to reflect on findings and change practice if necessary. The subcommittee sends each clinical service a confidential summary of its own results with aggregated data for comparison, as well as presenting national results at conferences and on the BHIVA website at www.bhiva.org

The subcommittee also seeks to publish its major findings in appropriate peer-reviewed journals. Articles to date include:

1. Ellis S, Curtis H, Ong ELC on behalf of the British HIV Association (BHIVA) and BHIVA Clinical Audit and Standards sub-committee. A survey of HIV care in the UK: results of British HIV Association (BHIVA) National Audit 2010. *Int J STD AIDS*, 2013, **24(4)**, 329–331.
2. Ellis S, Curtis H, Ong ELC on behalf of the British HIV Association (BHIVA) and BHIVA Clinical Audit and Standards sub-committee. HIV diagnoses and missed opportunities: results of the British HIV Association (BHIVA) National Audit 2010. *Clin Med*, 2012, **12(5)**, 430–434.
3. Garvey L, Curtis H, Brook G for BHIVA Audit and Standards Sub-Committee. The British HIV Association national audit on the management of subjects co-infected with HIV and hepatitis B/C. *Int J STD AIDS*, 2011, **22**, 173–176.
4. Backx M, Curtis H, Freedman A, Johnson M; BHIVA and BHIVA Clinical Audit Sub-Committee. British HIV Association national audit on the management of patients co-infected with tuberculosis and HIV. *Clin Med*, 2011, **11(3)**, 222–226.
5. Rodger A J, Curtis H, Sabin C, Johnson M; British HIV Association (BHIVA) and BHIVA Audit and Standards Subcommittee. Assessment of hospitalizations among HIV patients in the UK: a national cross-sectional survey. *Int J STD AIDS*, 2010, **21**, 752–754.
6. Street E, Curtis H, Sabin CA, Monteiro EF, Johnson MA, on behalf of the British HIV Association (BHIVA) and BHIVA Audit and Standards Sub-Committee. British HIV Association (BHIVA) national cohort outcomes audit of patients commencing antiretrovirals from naïve. *HIV Medicine*, 2009, **10**, 337–342.
7. Lomax N, Curtis H, Johnson M on behalf of the British HIV Association (BHIVA) and BHIVA Clinical Audit Sub-Committee. A national review of assessment and monitoring of HIV patients. *HIV Medicine*, 2009, **10**, 125–128.
8. Lucas SB, Curtis H, Johnson MA, on behalf of the British HIV Association (BHIVA) and BHIVA Audit and Standards Subcommittee. National review of deaths among HIV-infected adults. *Clinical Medicine*, 2008, **8**, 250–252.
9. Hart E, Curtis H, Wilkins E, Johnson M. On behalf of the BHIVA Audit and Standards Subcommittee. National review of first treatment change after starting highly active antiretroviral therapy in antiretroviral-naïve patients. *HIV Medicine*, 2007, **8**, 186–191.
10. De Silva S, Brook MG, Curtis H, Johnson M. On behalf of the BHIVA Audit and Standards Subcommittee. Survey of HIV and hepatitis B or C co-infection management in the UK 2004. *Int J STD AIDS*, 2006, **17**, 799–801.
11. Curtis H, Johnson MA, Brook MG. Re-audit of patients initiating antiretroviral therapy. *HIV Medicine*, 2006, **7**, 486.
12. McDonald C, Curtis H, de Ruiter A, Johnson MA, Welch J on behalf of the British HIV Association and the BHIVA Audit and Standards Subcommittee. National review of maternity care for women with HIV infection. *HIV Medicine*, 2006, **7**, 275–280.
13. Sullivan AK, Curtis H, Sabin CA, Johnson MA. Newly diagnosed HIV infections: review in UK and Ireland. *BMJ*, 2005, **330**, 1301–1302.

Other activities

Standards for HIV care

Standards of Care for People Living with HIV 2013 has been published following widespread consultation. The document was produced by BHIVA in partnership with a number of professional bodies. It includes 12 standards supported by rationale, quality statements and measurable, auditable outcomes, updating earlier standards published in 2007.

Patient-reported measures of care quality

BHIVA has been successful in obtaining funding from the MAC AIDS Foundation for a project to develop questionnaire tools to evaluate the impact of treatment and experiences of care from the perspective of people living with HIV in the UK. This work will continue in 2014.

Electronic records systems

The BHIVA Audit and Standards Subcommittee has been represented on a project supported by NHS Innovations, to develop the Climate™ HIV clinical record system initially produced at North Middlesex Hospital. This is now available to other NHS providers on a non-profit basis.

Surveillance reporting

The Information Standards Board for Health and Social Care has approved a new HIV and AIDS Reporting System data-set (HARS, Standard ISB 1570), which is intended to replace existing public health surveillance and provide information for commissioning NHS specialist HIV care in England. BHIVA surveyed its members in June 2013, and found that only 39% of relevant respondents were confident of being able to extract and report data in line with the HARS implementation schedule as it then stood.

Impact of the audit programme

A survey of BHIVA members found high awareness of the audit programme (88% and 85% for the last two projects) and good impact. The 2010–11 audit of new diagnoses and the 2011–12 audit of viral load outcomes/survey of psychological and adherence support had been of value in improving clinical practice for 62% and 52% of respondents respectively.

Further information

Details of previous BHIVA audits together with specimen questionnaires, findings and reports, the list of articles, and further resources are available on the BHIVA website at:

www.bhiva.org/AuditandClinicalStandards.aspx

Contact information

BHIVA Secretariat

Mediscript Ltd, 1 Mountview Court
 310 Friern Barnet Lane, London N20 0LD
 Tel: 020 8369 5380 Fax: 020 8446 9194
 Email: bhiva@bhiva.org Web: www.bhiva.org

Audit Co-ordinator

Hilary Curtis PhD, 39 Esmond Road, London NW6 7HF
 Tel: 020 7624 2148 Email: hilary@regordane.net

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Dr A Judd

Children's HIV Association

Mrs S Morris

Western General Hospital,
 Edinburgh

Mr D Ogden

HIV Pharmacy Association
 — to May 2013 —

Dr O Olarinde

Royal Hallamshire Hospital,
 Sheffield

Mr R Pebody

UK Community Advisory Board

Dr F Post

King's College London

Dr M Rayment

Homerton University Hospital,
 London

Dr A Rodger

Royal Free Hospital, London

Prof C Sabin

Royal Free and UCMS, London

Dr A Schwenk

North Middlesex Hospital

Dr A Sullivan

British Association for Sexual
 Health and HIV

Dr EGL Wilkins

North Manchester General
 Hospital

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