



Womack, J., Herieka, E., Gompels, M., Callaghan, S., Burt, E., Davies, C. F., ... Macleod, J. A. A. (2016). A novel strategy to reduce very late HIV diagnosis in high-prevalence areas in South-West England: serious incident audit. *Journal of Public Health*. DOI: [10.1093/pubmed/fdw007](https://doi.org/10.1093/pubmed/fdw007)

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**A novel strategy to reduce very late HIV diagnosis in high prevalence areas in South-West England: serious incident audit**

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Keywords : Public Health Practice, HIV, AIDS, late diagnosis, Serious Incident Reporting.

**Word count – 2998 (limit 3000), abstract 200 words, 1 table, 33 references**

**Target journal:** Journal Of Public Health

**Version V9\_13\_10\_2015**

**Abstract**

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**Background:** Very late diagnosis of HIV is a serious public health issue. We used serious incident reporting (SIR) to identify and address reasons for late diagnoses across the patient pathway.

**Methods:** Cases of very late HIV diagnosis were reported via SIR in two 6-month batches between 2011-2012 in Bournemouth, Poole, and Bristol. Case notes were reviewed for missed opportunities for earlier diagnosis using a root-cause analysis tool.

**Results:** 33 patients (aged 30-67 years, 66% male) were diagnosed very late. Although the majority were white British (n=17), Black African (n=9) and Eastern European (n=4) ethnicities were over-represented. 24 (73%) patients had clinical indicator conditions for HIV, 30 (91%) had a risk factor for HIV acquisition, with 13 (39%) having 2 or more (men-who-have-sex-with-men (n=11), partner HIV positive (n=11), from high prevalence area (n=12)). Actions resulting from SIR included increasing awareness of indicator conditions, HIV education days within primary care, and initiatives to increase testing within hospital specialities.

**Conclusions:** SIR allowed identification of reasons for very late HIV diagnosis and provided an impetus for initiatives to address them. SIR may be part of an effective strategy to prevent late diagnosis of HIV which would have important benefits for individual and population health.

## Introduction

In 2012 an estimated 100,000 people were living with HIV in the UK of whom approximately 22% were unaware of their infection(1). Of those individuals newly diagnosed with HIV, 47% were diagnosed late and 1 in 4 experienced a missed opportunity for an earlier diagnosis within the healthcare system in the preceding year(2, 3). Late diagnosis of HIV is associated with increased hospitalisations, decreased life expectancy (4-6), and higher treatment and care costs to the National Health Service (NHS)(7). Importantly, individuals with undiagnosed HIV are likely to be responsible for the majority of transmissions because successfully treated individuals are unlikely to infect others(8). Public Health England is committed to decreasing late HIV diagnoses which requires an understanding of their causes and whether there are missed opportunities in either primary or secondary care for earlier diagnosis.

Previous studies have researched correlates of late diagnosis and strategies to reduce late diagnosis of HIV in high prevalence areas (9). However, what is lacking is research on a mechanism for getting late diagnosis of HIV to be considered at a strategic level, and to understand how to trigger appropriate action at the local level based on procedures in usual clinical practice. However, there is a good system within secondary healthcare to notify, investigate, and influence using the serious incident reporting (SIR) procedure which has not previously been used to inform changes that might result in earlier HIV diagnosis.

In 2011 the Office for Sexual Health under guidance from the South West Sexual Health Board established a pilot study on very late diagnosis of HIV. The sexual

health lead invited NHS Bournemouth and Poole, and NHS Bristol (including North Somerset and South Gloucester) to pilot a review of all cases of very late diagnosis of HIV in line with the national framework for reporting and learning from serious adverse incidents. These primary care trusts (PCTs) were chosen because their diagnosed HIV prevalence was around the threshold of 2/1000 adult population (10) above which National Institute for Health and Care Excellence guidelines recommend routinely offering HIV tests to new registrants in primary care (PC) and to people from high risk groups such as black Africans and men-who-have-sex-with-men (MSM)(11,12).

The primary aim of the study was to pilot the use of SIR to allow a root-cause analysis of very late HIV diagnosis in both primary and secondary care, and to formulate and implement an action plan based on the causes identified. The secondary aim was to qualitatively assess whether the SIR process was an effective catalyst for improving access to testing and preventing very late HIV diagnosis. Fundamentally, we wished to understand the effect of SIR across the health community as a public health intervention, rather than focusing on the acute setting where the SIR was triggered in isolation.

## **METHODOLOGY**

The project was coordinated by the South West Office for Sexual Health (England) which established a team of clinicians, commissioners, consultants in Public Health, as well as academic and PC representation from NHS Bournemouth and Poole, and NHS Bristol. Support was sought from the NHS South of England Patient Safety Team, Chief Executives, Medical Directors, and Directors of Public Health in the relevant PC

and NHS Trusts. The Royal Bournemouth and Christchurch Hospital Genitourinary Medicine (GUM) Department and the North Bristol NHS Trust HIV Department provide care for over 800 HIV patients in the Bournemouth and Poole area, and over 1000 HIV patients from Bristol and surrounding areas, respectively.

Current UK guidelines recommend that antiretroviral therapy should be started in patients with a CD4 count below 350 cells/mm<sup>3</sup>(13-14). Late diagnosis of HIV is defined as patients with a CD4 count within 3 months of diagnosis of <350 cells/mm<sup>3</sup> and very late <200cells/mm<sup>3</sup> or with an AIDS defining condition (15-16). The project reported as serious incidents all cases of very late diagnosis between January and June 2011 in Bristol and between June and December 2011 in Bournemouth and Poole (Audit 1). The incidents were reported as a batch and submitted via the Strategic Executive Information System (StEIS) in February 2012. The SIR process was complied with and action plans produced. Data on a second batch of late diagnoses from January to June 2012 were collected at both sites and submitted in September 2012 (Audit 2).

We developed a root-cause analysis (RCA) tool (see supplementary material) to determine whether patients had previously presented with risk factors or clinical indicators for HIV. RCA aims to identify the origin of a problem using a specific set of steps with associated tools to find the primary cause. The standards underpinning the tool were taken from the UK guidelines for HIV testing (13). In addition a protocol and case review template for hospital and PC data collection were also developed. Notes of all newly diagnosed patients were screened and patients not from the relevant

areas or with a CD4 count  $>200$  cells/mm<sup>3</sup> at diagnosis were excluded. For each case, demographic characteristics, clinical indicator (CI) conditions, CD4 count, risk factors and prior visits to a General Practitioner (GP) or hospital were collated from the medical records. The patient was consented and a case review request was sent to their GP and/or hospital clinician as appropriate. The review assessed further information on the patient's history, GPs'/clinicians' knowledge of CI conditions, what steps they were taking to increase HIV testing and whether support or education was required. The GUM/HIV consultant followed up all responding GPs'/clinicians by letter with full RCA containing information and advice on recognising CIs. In December 2012 the project group analysed the audit data and recommended interventions to prevent future occurrence of late diagnoses.

## **RESULTS**

In Bournemouth and Poole during the year of the audit 46 people were newly diagnosed with HIV of whom 31 (67%) had a CD4 count below 350 cells/mm<sup>3</sup> and 19 (41%) were very late diagnoses. The corresponding figures for Bristol were: 56 new diagnoses of HIV, of whom 32 (57%) and 21 (38%) were late and very late diagnoses, respectively. Across both areas, 7/40 identified individuals were excluded from the audit as they either did not live in the area, had a previous positive test but had fallen out of treatment, or had a positive test abroad and delayed access to treatment until returning to the UK. Table 1 shows the summary of characteristics of the 33 patients included in the two-stage audit by area. Their ages ranged from 30 to 67 years, and 21 (66%) were male. Black African (27%) and Eastern European

(12%) ethnicities were over-represented compared with the background population, although the majority were white British (52%). Nearly all patients had at least one risk factor for HIV acquisition, 13 (39%) had two or more, and one three risk factors. Frequently identified risk factors were: MSM (n=11), partner HIV-positive (n=11), patient from a high prevalence area (n=7), or from sub Saharan Africa (n=5).

The proportion of patients diagnosed in secondary care was very high in Bournemouth and Poole (14/15, 93%) and lower in Bristol (10/18, 56%). The review process in PC was successfully completed in 11/15 and 15/18 cases in Bournemouth and Poole, and Bristol, respectively. Attendance within PC in the year preceding diagnosis was high with many patients presenting on numerous occasions. There was no evidence that individuals had refused a test, although one Bristol patient initially refused but then agreed to test within the same care episode. A high proportion of patients had HIV CIs including recurrent mouth ulcers, weight loss, skin lesions, pneumocystis pneumonia, tuberculosis, shingles, chronic diarrhoea, unexplained blood dyscrasia, lymphadenopathy, oral candidiasis and STIs. The following case illustrates multiple missed opportunities for testing based on CI presentation. The patient registered with a GP practice in 2010, was diagnosed with tuberculosis later that year, and then re-presented to PC in February 2011 with persistent cough, loin pain and night sweats. The patient was admitted to hospital in March 2011 with generalised abdominal pain, but was not diagnosed with HIV until March 2012.



As a result of the SIR and audit in Bournemouth and Poole, programmes to increase awareness of CIs for HIV and testing guidance were developed for use in PC. An HIV practice website was developed, GPs attended in-house education during practice meetings and education days, and a pilot testing programme was launched in a higher prevalence area which invited patients to test.

Work was done to increase HIV testing within hospital specialties. A campaign increased awareness of specific CIs within the Emergency Department. Consultants agreed to test patients who had any HIV CIs. This is now official policy, with posters of CIs displayed in all departments. Monthly HIV educational update sessions were held for staff at Poole Hospital with feedback of laboratory HIV positivity rates. The Royal College of Emergency Medicine was successfully lobbied to change HIV testing recommendations.

On a strategic level, measures were undertaken to ensure late diagnosis remained a priority within the local authority. A sexual health commissioning intention strategy was agreed across commissioning and provider organisations. Increased testing was commissioned in core sexual health services (e.g pregnancy termination and community sexual health). A training plan was developed for health professionals to improve knowledge of CIs. A community testing programme targeting very high risk groups for education events and testing was established. A tendering process is underway to develop more integrated sexual health services and to develop outreach GUM clinics in high prevalence areas. Since enhanced testing was

introduced in Bournemouth and Poole late diagnosis has decreased from 50% to 32%.

In Bristol there was no evidence to suggest impaired access to HIV testing in secondary care as patients with risk factors appeared to be testing appropriately as part of the diagnostic process. This may be due to previous engagement of the HIV service with clinical teams to raise the profile of HIV testing in hospital clinics. There was, however, evidence of missed opportunities for testing in PC. A sexual health annual study day was held for practice nurses and GPs during which the audit data and issues relating to very late diagnosis were presented. Practices were encouraged to offer HIV testing at the point of registration to individuals from high prevalence countries. A web link and presentation slides on guidance for testing such individuals was made available for GPs and nurses, which resulted in requests for further training on HIV. In GP and hospital settings in Bristol and Bournemouth and Poole, testing increased by 5% and 6%, respectively, between 2012-13.

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## **DISCUSSION**

### ***Main findings of this study***

Our study showed that SIR of very late HIV diagnoses in six month batches was an effective intervention for raising awareness across the health community. The audit found many missed opportunities for earlier HIV diagnosis, particularly in PC. Patients were accessing health services with opportunistic infections, ranging from 0-11 times, before an HIV test was offered, supporting the need to improve

recognition of HIV CIs. In PC, testing was not considered even when there were multiple CIs for HIV because the focus was on diagnosis for individual symptoms which led to referral for unnecessary procedures and investigations. Although risk factors were recorded in the majority of notes, they were not considered alongside CIs as part of a more holistic diagnosis to request an HIV test. Failure to assess risk was more likely when individuals presenting were at a low perceived risk (e.g white, European, married) and not from the standard high risk groups.

***What is already known on this topic***

Our audit of very late HIV diagnosis supports previous literature on both the predominant modes of HIV transmission and in terms of specific groups or communities where late diagnoses most frequently occurs(17-18), for example, in older adults (19-20). HIV testing, which is free and confidential at services such as STI clinics, should be promoted among higher risk groups to ensure individuals are aware of their HIV status. MSM are recommended to have an HIV/STI screen at least annually, and every three months if having unprotected sex with new or casual partners. Black Africans and Caribbeans should have an HIV test with repeat screening if having unprotected sex with new or casual partners.

Barriers to testing may be greater for the healthcare professionals than for patients (21). Reasons for not testing include insufficient time, competing priorities, inadequate knowledge/training, perceived burdensome consent process and pre-test discussion, low risk populations and fear/concern of offending the patient(22-23). Previous studies reported the need for education and training on HIV testing for

GPs (24-25). Some still perceive requesting an HIV test as a specialist role that cannot be offered outside a specialist setting, such as GUM, despite BHIVA guidelines (2008) stating that no special competencies are required to consent for and conduct an HIV test (13).

There are capacity, cost and policy implications for practices in addition to training, engagement and acceptance of normalising HIV testing. In 2012 the Health Protection Agency presented to commissioners of sexual health and HIV services the evidence on acceptability, feasibility, clinical benefit and cost-effectiveness of expanding HIV testing in general medical admissions and new registrants in general practice. The routine offer of an HIV test was shown to be acceptable to patients and feasible in a variety of medical settings (9). The key to earlier diagnosis is to normalise testing within a range of groups (26). In higher prevalence settings, opt-out (27) and routine HIV testing strategies have been advocated in PC (28) which are less stigmatising and therefore more acceptable to high risk groups(27,29). Although routine, not targeted, testing was often the commonest reason for people accessing testing(30-31), targeted testing may be more appropriate in lower prevalence settings.

#### ***What this study adds***

Two key aspects of our study were submitting data in batches to provide sufficient cases to compare and identify trends, and recognising that the SIR process should relate to the entire patient pathway and involve the whole health community. Unlike audit which focuses on one aspect of the NHS, the SIR process allowed

organisational responsibility for very late HIV diagnosis to be correctly apportioned across the NHS. In addition, SIR facilitated systematic review of cases to improve detection and consideration of the issue at a senior level within organisations thereby informing population testing strategies.

This pilot was undertaken at a time of significant change to health systems in the UK and was seen as an opportunity to influence NHS England and the Clinical Commissioning Groups (CCG) established after April 2013, which are responsible for PC. The responsibility for local public health previously based in PCTs was transferred to local authorities, which are now responsible for commissioning HIV testing in community settings. Presentations of this audit in a range of settings and the importance placed on SIR made the case for the need to commission improved HIV testing opportunities. Highlighting the issues surrounding very late diagnosis and the timely multi-agency drive for education on CIs and testing gave healthcare staff access to training, support and updated HIV testing pathways. This support was disseminated to all GPs across Dorset and community sexual health staff through sexual health strategic and delivery groups to encourage engagement and motivation.

In Bristol, missed opportunities for testing were apparent in primary, but not secondary care. GPs were encouraged to offer tests to new registrants from high prevalence countries. However, completion of the full SIR process was disrupted due to the coincidence of timing of the 2013 NHS reorganisation and associated changes in commissioning structure.

### ***Limitations***

Our study was a pilot and therefore numbers of new diagnoses during the study period were only just over 100. The audit was restricted to two centres in SW England, but may be generalizable to medium prevalence cities elsewhere in the UK, particularly those with higher levels of late diagnoses than the national average. The audit revealed that, due to the way screening information is collected on GP systems, there was limited documented evidence of when a test had been offered or refused. These data are critical for determining which interventions would be effective in reducing late diagnosis. Dates of diagnosis of CI conditions were not recorded in this study, but could be used to evaluate the economic and clinical impact of delay in diagnosis from the first missed opportunity. This pilot study only followed up individuals diagnosed with very advanced HIV disease, but SIR could be extended to include those with a late diagnosis of HIV ( CD4 <350cells/mm<sup>3</sup> at presentation) as this cohort also requires investigation.

### ***Conclusions and Recommendations***

Increased testing in PC needs to be a commissioning priority. Screening new registrants particularly for people from high prevalence areas and opt-out testing should be considered in higher prevalence practices. This would normalise HIV testing, remove stigma, and increase access. There needs to be a change in cultural practice beliefs that HIV awareness and testing is a specialist role that cannot be

offered outside a specialist setting. Barriers to testing must be addressed to ensure patients receive a prompt and early diagnosis of HIV.

Key messages are that many opportunities, particularly in PC, are missed for earlier HIV diagnosis and that documentation of HIV testing needs improving. HIV testing should be added to the GP system with date of test offer, and whether an HIV test was given or refused. Support at national level is required to improve recording in PC. Health professionals require ongoing education in recognising HIV CI conditions and risk factors for HIV acquisition(32-33). SIR provides a mechanism to investigate very late diagnosis and use the information to influence practice in PC and other specialties, and could change testing strategies across the health community.

Although reporting cases of late diagnosis increases the workload, it does have a crucial effect on relaying issues to other sectors. Furthermore, late diagnosis is proportionally less in areas of high prevalence due to greater awareness of the likelihood of HIV (1).

Late HIV diagnosis should continue to be monitored and SIR considered in other regions wanting to reduce late and very late diagnosis of HIV.

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## **Funding**

This work was supported by the South West Office for Sexual Health which was funded by the Department of Health. MM is funded by the UK Medical Research Council [grant number MR/J002380/1] and the Department for International Development (DFID).

## **Acknowledgements**

The authors would like to acknowledge the work of Dr Louise Downs (Registrar), Dr Harriet Nichols (Registrar) and Sally Palmer (Sexual Health Advisor) of the Royal Bournemouth and Christchurch Hospital. Acknowledgement is also made to the work of Elizabeth Williams and Dr Joe Sawyer of the North Bristol NHS Trust, Southmead Hospital. In Bristol, this project was undertaken with the support of the “Health Integration Team” SHIPP (Sexual Health Improvement for Populations and Patients <http://www.bristolhealthpartners.org.uk/health-integration-teams/sexual-health-improvement-hit/>) and the NIHR Health Protection Research Unit in Evaluation of Interventions. The views expressed are those of the authors and not necessarily those of the NHS, the NIHR, the Department of Health or Public Health England.

## **Author contributions**

JW conceived the study in discussion with JM, MG and EB. JW drafted the first version of the paper. JW, EH, MG, SC, EB, NOB, and JM contributed to the study design. JW, EH, MG, SC, EB and CD helped with data collection. All authors



contributed to interpreting data, drafting the article, revising it and have approved the final version of the manuscript.

**Conflicts of interest**

The authors have no conflicts of interest

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