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### ORIGINAL RESEARCH



# Monitoring of older HIV-1-positive adults by HIV clinics in the United Kingdom: a national quality improvement initiative

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#### **Objectives**

The aim of the study was to describe a UK-wide process to assess adherence to guidelines for the routine investigation and monitoring of HIV-positive adults aged ≥ 50 years and provide clinical services with individual feedback to support improvement in quality of care.

The British HIV Association (BHIVA) invited HIV clinical care sites to provide retrospective data from case notes of up to 40 adults aged ≥ 50 years with HIV-1 infection attending the clinic for care during 2017 and/or 2018, using a structured dynamic online questionnaire.

#### Results

A total of 4959 questionnaires from 141 clinical services were returned. Regarding the key targets specified in the BHIVA monitoring guidelines, 97% of patients on antiretroviral therapy (ART) had had their viral load measured in the last 9 months, or 15 months if on a protease inhibitor, and 94% had had all medications recorded in the last 15 months. Only 67% of patients on ART without cardiovascular disease (CVD) had had a 10-year CVD risk calculated in the last 3 years. It was reported that 80% and 92% had had their smoking status documented in the last 2 years and blood pressure checked in the last 15 months, respectively. HIV services had communicated with the general practitioners of 90% of consenting individuals, but consulted electronic primary care records for only 10%.

#### Conclusions

Nationally, targets were met for viral load and blood pressure monitoring but not for CVD risk assessment, smoking status documentation and recording of comedication. There was variable performance in relation to other outcomes; adherence and laboratory measurements were carried out more regularly than lifestyle and wellbeing assessments.

Keywords: care quality, comorbidities, HIV, older patients, polypharmacy

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#### Introduction

In 2017, 39% of people seen for HIV care in the UK were aged  $\geq$  50 years [1]. This proportion is rising as excellent

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antiretroviral therapy (ART) outcomes continue to contribute to increased life expectancy, and increased HIV testing results in more diagnoses in this age group. While this is welcomed, ageing among people with HIV infection presents increasing scope for non-HIV-related comorbidity and polypharmacy.

Frequently encountered comorbidities in people with HIV infection include cardiovascular disease (CVD), hypertension, dyslipidaemia, renal impairment and osteoporosis [2,3]; regular screening for these conditions is recommended in this population. High rates of isolation and depression have also been recognized in people living with HIV [4]. Screening and identification of any psychological concerns in older people with HIV infection should not be neglected, especially as mental health problems may have a negative impact on ART adherence. Compared with the general population, a higher proportion of people with HIV infection do not have contact with a general practitioner (GP). There are multiple reasons for this, although a concern around HIV-related stigma is likely to play a key role; the 2015 Stigma Survey UK revealed that one in eight HIV-positive participants had avoided seeking health care at their general practice in the previous 12 months when it was required [5]. This group may therefore miss out on opportunities for general health monitoring and modifiable risk assessment, placing an additional burden on HIV clinicians who may be their only health care contact.

Alongside ART prescribed by HIV clinicians, people with HIV infection may receive prescribed comedication from primary care and other specialities. The number of medications taken increases with advancing age [6]. Inadequate communication presents a risk of missed drug—drug interactions, some of which can result in significant morbidity [6–8]. Specialist clinical services can also obtain GP-provided information about medical history, prescriptions and immunizations via the Summary Care Record (SCR), which is accessible via the National Health Service (NHS) data spine, and covers 96% of people in England [9]. This is a useful tool for HIV services to obtain key information about co-prescribed medications.

The British HIV Association (BHIVA) is the leading UK association representing health professionals in HIV care. It has published guidelines for the monitoring of adults infected with HIV-1 [10] with measurable targets, alongside standards of care [11] which provide further recommendations for good practice, such as the need for routine GP communication and psychological screening. Following earlier national reviews which found poor rates of recording of CVD and fracture risk assessment [12] and psychological screening [13], BHIVA sought to review quality of care specifically for older adults, to assess if there had been improvements. This article describes the review process used in the UK and highlights the potential for similar methods to facilitate care quality improvement and prevention of noncommunicable diseases in people with HIV infection in high-, middle- and lowincome countries.

#### Methods

Design and data collection

The BHIVA Audit and Standards Sub-Committee invited all UK specialist HIV clinical services to complete a retrospective case note review of up to 40 adults aged  $\geq 50$  years attending the clinic for routine care for HIV-1 infection during 2017–2018 up to the time of data collection. Services with fewer than 40 such eligible attendees were asked to review all of these. People with HIV-2 infection were excluded, as were those attending for other, nonroutine care reasons, for example for the investigation of new symptoms.

Responses were submitted electronically via a dynamic online web-based questionnaire, with each service being identified via a unique code. The following data were requested from participating clinics under the five sections listed below.

#### Patient characteristics

The clinics were required to provide the following data for each patient, gender, age, HIV exposure risk and ethnicity.

#### HIV management

The most recent CD4 cell count and, for people on ART, whether the regimen included a protease inhibitor (PI) and the dates on which viral load and adherence were last assessed were requested.

#### Medicines management

The following data were requested for submission: the date on which a list of all current medications was last recorded; the number of non-ART medications received; whether the NHS data spine/Summary Care Record (SCR) or equivalent had been consulted to check prescribed medications; and whether individuals had been asked about the use of overthe-counter (OTC) medication and herbal remedies within the past 3 years. For individuals with co-prescribed medications, respondents were asked whether it was documented that the potential for drug—drug interactions had been considered and pharmaco-kinetics reviewed.

#### Communication and shared care of comorbidities

The following data were requested for submission: whether individuals were registered with a GP and, if so, had given consent for communication; for those who had provided consent, dates of last communication from the HIV service to the GP and vice versa; presence or absence of eight common comorbidities (hypertension, hyperlipidaemia, type 2 diabetes, CVD, renal impairment, depression with or without anxiety, osteoporosis and obesity) and, if present, whether recently diagnosed or long-term, with an

additional free-text option for other comorbidities of current clinical concern; whether there had been good communication about the management of comorbidities that were recently diagnosed or of current concern.

#### Monitoring

The following data were requested for submission: dates of last recorded 10-year CVD risk and fracture/bone fracture risk assessment tool (FRAX) or dual-energy X-ray absorptiometry (DEXA) assessments, and blood pressure, weight, glucose, lipid and urinalysis measurements; dates of last documented enquiry about smoking, alcohol, recreational drug use, sexual partners, state of mood/mental health and memory/cognition; for individuals coinfected with hepatitis B and/or C virus, date of last screening for hepatocellular carcinoma (HCC). Further questions asked about documentation of the offer of sexually transmitted infection (STI) screen, menopausal status (for women to age 56 years), annual cervical cytology (for women to age 65 years), and annual influenza and pneumococcal vaccinations.

#### Ethical approval

Ethical approval and informed consent were not required as this was a clinical audit based on routinely collected data and no patient identifiable details were collected.

#### Data analysis

Data were collected during May to July 2018 using LimeSurvey online software (LimeSurvey GmbH, Hamburg, Germany) and analysed in Microsoft® excel 2010 (Microsoft Corporation, Redmond, WA).

#### Feedback to HIV services

Each site had the option to request a rapid analysis of their performance against key auditable targets immediately after completing data submission. Following presentation at the BHIVA 2018 autumn conference [14], sites received a full report of performance in comparison with national data and site-level quartiles, with recommendations by the BHIVA Audit and Standards Sub-Committee on how to make improvements. An audit annual report was also uploaded to the BHIVA website [15].

#### Results

#### Demographics

A total of 4959 forms from 141 clinical services were completed. This represents 5% of the 93 385 people

reported by Public Health England to be living with HIV and assessing care in the UK in 2017 [16], and 14% of those > 50 years of age (total 36 288) [1]. Three-quarters of individuals were male, > 90% had acquired HIV through a sexual route, two-thirds of individuals were aged 50–59 years and two-thirds were of white ethnicity (Table 1). The majority of individuals (4148; 84%) had been receiving long-term care at their current HIV service. Of the 811 (16%) who first attended their current clinic during or after 2015, 421 (9%) and 304 (7%), respectively, had transferred care from another HIV service and had newly diagnosed infection. Only 15 (0.3%) individuals had been previously out of care, and information was lacking for 11 (0.2%).

Significant rates of comorbidity were recorded, with prevalences of specified listed conditions being: hypertension, 31%; hyperlipidaemia, 31%; depression with or without anxiety, 24%; renal impairment, 15%; CVD, 12%; obesity, 11%; type 2 diabetes, 11%; osteoporosis, 5%. These prevalences increased with age (Fig. 1), with 63% of individuals aged > 70 years having at least two of the listed comorbidities compared with 37% of those aged 50–54 years. Overall, 29% of individuals had at least one non-HIV-related condition of current clinical concern, comprising 334 (7%) with recent onset or diagnosis of the listed conditions; 941 (19%) with other conditions that were recently diagnosed or poorly controlled, including malignancies, chronic obstructive pulmonary disease (COPD), asthma and arthritis; and 160 (3%) with both.

Table 1 Demographics for patients included in this study

	National n (%)
Total	4959 (100)
Gender	
Male	3638 (73.4)
Female	1280 (25.8)
Trans	7 (0.1)
Not answered	34 (0.7)
Mode of HIV acquisition	
Sex between men and women	2371 (47.8)
Sex between men	2219 (44.7)
Injecting drug use	68 (1.4)
Other	66 (1.3)
Not known/answered	235 (4.7)
Age	
50–54 years	1876 (37.8)
55–59 years	1407 (28.4)
60–64 years	775 (15.6)
65–69 years	470 (9.5)
≥ 70 years	414 (8.3)
Not answered	17 (0.3
Ethnicity	
White	3323 (67.0)
Black-African	990 (20.0)
Other	532 (10.7)
Not stated/answered	114 (2.3)

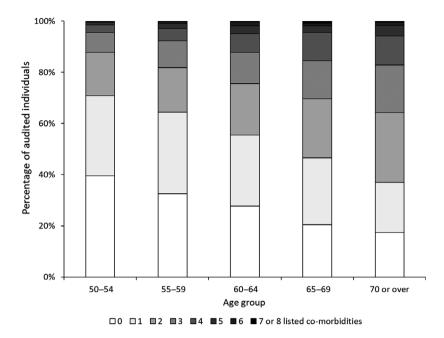


Fig. 1 Relationship between age and number of specified listed comorbidities.

#### Key target outcomes

Results for the key outcomes with targets specified in guidelines were as shown in Table 2. Nationally, 97% (4718 of 4852) individuals on ART had viral load measured within the past 9 months, or 15 months if they were taking a PI-based regimen. Most sites performed well on this, meeting the 90% target [median 98%; interquartile range (IQR) 95–100%]. All medication had

Table 2 Results of key target outcomes specified in 2016 British HIV Association (BHIVA) monitoring quidelines

Outcome	n	%	Target (%)	Site median (IQR) (%)
People on ART (n = 4852) with VL measured within last 9 months, or 15 months if on Pl	4718	97.2	90	97.5 (95.0–100.0)
People on ART ( <i>n</i> = 4852) with all medications recorded within last 15 months	4555	93.7	97	97.3 (92.3–100.0)
People on ART and without CVD (n = 4293) with 10-year CVD risk calculated within last 3 years	2879	67.1	90	73.1 (50.0–92.1)
Smoking history documented in last 2 years	3989	80.4	90	90.0 (70.0–97.5)
Blood pressure recorded in last 15 months	4552	91.8	90	95.0 (90.0–100.0)

ART, antiretroviral therapy; CVD, cardiovascular disease; IQR, interquartile range; PI, protease inhibitor; VL, HIV viral load.

been recorded within the past 15 months for 94% (4555 of 4852) individuals on ART, slightly short of the target of 97%. The 90% target for blood pressure measurement was also met, with 92% (4552) of patients having had this recorded in the last 15 months. Smoking history and 10-year CVD risk calculation targets were not met, being documented for only 80% (3989) and 67% (2879 of 4293 individuals on ART without CVD), respectively, within the specified time-scales.

In comparison to the 2015 BHIVA national review of routine monitoring and investigations [12], there were improvements in all five key targets (Table 3), but there was still room for further improvement, especially in relation to CVD.

#### Recording of other monitoring

Results for other routine monitoring and lifestyle questions are shown in Table 4. Performance varied but was generally better for monitoring of adherence and laboratory measurements as compared with recording of wellbeing, lifestyle and fracture/bone assessment.

#### Medicines management

Polypharmacy increased with age, with the proportion of individuals taking at least four co-prescribed non-ART medications being 24%, 38% and 51% for those in their 50s, 60s and 70s, respectively. It was documented that

Table 3 Comparison of 2015 and 2018 British HIV Association (BHIVA) national review results: key target outcomes for those aged ≥ 50 years

	2015	2018		
	% ( <i>n</i> /total)	% ( <i>n</i> /total)	$P(\chi^2)$	Target (%)
VL measured*	91.8 (2234/2434)	97.2 (4718/4852)	< 0.001	90*
Medications recorded	89.9 (2189/2434)	93.9 (4555/4852)	< 0.001	97
CVD risk assessed	50.6 (1049/2074)	67.1 (2879/4293)	< 0.001	90
BP recorded	87.5 (2246/2568)	91.8 (4552/4959)	< 0.001	90
Smoking status recorded	67.8 (1741/2568)	80.4 (3989/4959)	< 0.001	90

BP, blood pressure; CVD, cardiovascular disease; VL, HIV viral load.

Table 4 Recording of other monitoring outcomes: number (%) within 15 months, unless otherwise specified

	National n (%)
ART management	
Adherence if on ART ( $N = 4852$ )	4536 (93.5
Recorded measurements	
Weight or BMI	4389 (88.5
Random glucose or HbA1c	3962 (79.9
Random lipid profile	4466 (90.1
Urinalysis or uP/C	4148 (83.7
Bone/fracture assessment	
FRAX score or DEXA scan recorded in past 3 years	2247 (45.3
Recorded assessments of psychological wellbeing and substance	use
Mood/mental health	3495 (70.5
Memory/cognition	1367 (27.6
Alcohol use	3455 (69.7
Recreational drug use	2953 (59.5
Sexual health	
Sexual partners and possible PN review recorded	3124 (63.0
Offer of sexual health screen recorded	3075 (62.0
Syphilis serology tested	3668 (74.0
Cervical cytology done, or advised to request (women $\leq$ 65 years old, $N=1137$ nationally)	768 (67.5
Menopause status recorded (women $\leq 56$ years old, $N = 739$ )	511 (69.1
Immunization	
Recorded that received/advised about flu vaccine (last season)	1924 (59.6
Recorded that received pneumococcus vaccine (ever)	1690 (34.1

ART, antiretroviral therapy; BMI, body mass index; DEXA, dual-energy X-ray absorptiometry; FRAX, fracture risk assessment tool; HbA1c, glycated haemoglobin A1c; PN, partner notification; uP/C, urine protein creatinine ratio.

3423 (69%) individuals had been asked about nonprescribed OTC medication and 2710 (56%) about herbal or traditional remedies in the preceding 3 years.

#### Communication and shared care of comorbidities

Nationally, 4800 (96.8%) of the audited individuals were registered with a GP and 4431 (89%) had consented for the HIV service to communicate with their GP (site median 91%; IQR 84–95%). There had been communication from the HIV service to the GP within the previous 15 months for 3976 (90%) of consenting individuals but

communication from the GP to the HIV service was recorded for only 328 (7%). The SCR had been consulted to check information about prescribed medications for 9% (413 of 4420) of audited individuals in England. In Scotland and Northern Ireland, an equivalent of the SCR had been checked for 29% (71 of 242) and 58% (15 of 26) individuals, respectively. Nearly half of participating sites (64 of 132) in England, Scotland or Northern Ireland did not report checking the SCR or an equivalent for any of their patients.

#### Discussion

Our study population represented 14% (4959 of 36 288) of adults aged ≥ 50 years and accessing HIV care in the UK [1] and revealed high rates of comorbidity and polypharmacy which, as expected, increased with age. The median age of people receiving HIV care is increasing [1,2], and as two-thirds of audited individuals were aged 50-59 years, increasing clinical complexity can be expected with further ageing among people living with HIV in the UK. This requires effective evidence-based screening and monitoring, as suboptimal management of comorbidities and polypharmacy can lead to risks of drug toxicity, reduced adherence to life-extending ART, drugdrug interactions, less cost-effective prescribing, frailty and mortality [2,3,6-8]. SCR review and full medicines reconciliation with patients and their carers at least annually may help prevent potential dangers associated with polypharmacy in the ageing HIV-infected cohort [7]. Some HIV services have found the development of clinics specifically designed for older patients a viable and effective option in managing the challenges in this population [17,18]. This may become more common in the future, resulting in a shift from standard care of ageing people living with HIV with targeted disease-specific management to a more holistic geriatric-based approach [19] where maintenance of quality of life forms part of the overall therapeutic goal.

In terms of our review outcomes, guideline targets were met nationally and by most individual sites for viral load

<sup>\*</sup>Guidelines outcome and target changed: 2015 within 6 months (80%); 2018 within 9 months or 15 if on a protease inhibitor (90%).

monitoring and blood pressure measurement, but not for CVD risk assessment, smoking history or co-medication documentation. The poorest outcome was for CVD risk calculation, although the most common reported comorbidities were hypertension and hyperlipidaemia, both of which are CVD risk factors. CVD significantly contributes to non-AIDS-related morbidity and mortality in people living with HIV and has a multifactorial aetiology involving interplay between traditional risk factors and HIVspecific factors such as HIV viraemia, immune dysfunction and the pro-inflammatory state associated with HIV infection [2,3,20]. Interventions proven to reduce CVD in the general population such as smoking cessation have been demonstrated to be beneficial in people living with HIV [21]. BHIVA guidelines still recommend addressing traditional modifiable risks alongside choosing ART regimens with favourable metabolic profiles where applicable [22]. Encouragingly, there were significant improvements in all key outcomes compared with an earlier audit in 2015 [12], suggesting that the model of national collection and analysis of data followed by individual feedback to clinical services can be effective in supporting local improvement in quality of care.

The World Health Organization (WHO) reports that deaths from CVD, diabetes and cancer in Africa are rising faster than anywhere else in the world [23]. In sub-Saharan Africa, HIV treatment is more readily available today than in previous decades, but it is not accompanied by services for these noncommunicable diseases [24]. Some patients have access to the same treatments available in high-income countries, but most do not. Therefore, prevention and early identification of these noncommunicable diseases is paramount if we are to avoid further premature deaths and long-term morbidity. BHIVA's approach of setting clinical guidelines and targets for monitoring and investigations in people living with HIV, supported by a national but voluntary system of data collection, analysis and feedback, may serve as a model for supporting quality improvement in managing comorbidities in this population which could be adopted more widely across high-, middle- and low-income country settings. For example, the European AIDS Clinical Society has drawn on BHIVA's experience in seeking to set standards and auditable targets to improve HIV care, although in this case with a focus on hepatitis and tuberculosis coinfection and late HIV presentation, especially in Eastern Europe [25].

Apart from key target outcomes specified in guidelines, monitoring of other outcomes was variable, with the lowest recorded rates being for bone/fracture risk assessment and asking about memory or cognition. Rates of monitoring of adherence and laboratory measurements were higher than those for wellbeing and lifestyle. It is of concern that only 71% of individuals had been asked about their mood or mental health, given that 50% of people living with HIV reported symptoms of depression and anxiety in the Stigma survey [5]. In that survey, the greatest unmet need was for help dealing with isolation and loneliness, with one in five people living with HIV needing this help. This psychological challenge is likely to be accelerated in the ageing HIV-infected population. However, the 2018 audit showed some improvement over BHIVA's 2017 national audit in this respect [13], as psychological wellbeing/mental health was documented or asked about for only 64% of individuals aged  $\geq$  50 years in the 2017 audit.

#### Limitations

As data collection was by retrospective case note review, it is not possible to determine the extent to which the results reflect documentation and reporting rather than actual performance of monitoring interventions. In particular, in some clinics, review of the SCR or NHS data spine for potential drug—drug interactions may be carried out by pharmacists, who may or may not document this in the medical notes. Although we endeavoured to obtain information about HCC screening in individuals with hepatitis B/C virus coinfection, we have not reported results because the quality of these data appeared poor and investigations could have been carried out by the hepatology department and not documented within the HIV service.

#### Recommendations and conclusions

Performance for outcomes assessed in this project varied widely between HIV services, but was generally better for HIV-specific care and laboratory measurements than for CVD and bone/fracture risk assessment and recording of wellbeing and lifestyle. In the light of these findings, we recommend that clinics should have agreed methods locally to achieve standards specified in guidelines, including but not limited to the use of standardized clinical documentation proformas, where feasible, as prompts to these often forgotten questions and assessments. Clinic policies can recommend annual review consultations, with standard guidance to clinicians on investigations and assessments to be included in this in-depth annual monitoring. Where electronic patient records and appointment systems are in use, these could be set up to provide automated reminders for annual review.

More generally, we have shown that clinician-led national review of care standards, based on voluntary collection of retrospective case-note data, is feasible. Feedback of individualized reports enables clinicians to see how their service's outcomes compare with national data, aiding motivation and prioritization of issues for local quality improvement. While any such approach should be adapted to local needs and circumstances, we believe that BHIVA's national review framework represents an example of good practice which could inform care quality improvement initiatives in other high-, middle- and low-income country settings.

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#### Authors' contributions

HC and NE contributed to planning and design. HC conducted data analysis. All authors contributed to drafting the manuscript and interpretation of findings and approved the final version.

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