Abstract

Introduction:

Aim:

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

Methods:

The British HIV Association (BHIVA) invited HIV clinical care sites to provide retrospective data from case notes of up to 40 adults aged 50 and over with HIV-1 infection attending during 2017 and/or 2018, using a structured dynamic online questionnaire. Data were analysed centrally and findings reported back to participating sites.

Results:

A total of 4959 questionnaires from 141 clinical services were returned. Of the key targets specified in the BHIVA monitoring guidelines, 97% of patients on antiretroviral therapy (ART) had viral load measured in the last 9 months or 15 months if on a protease inhibitor. 94% had all medications recorded in the last 15 months. Only 67% of patients on ART without cardiovascular disease (CVD) had a 10-year CVD risk calculated in the last 3 years. 80% and 92% had their smoking status documented in the last 2 years and blood pressure checked in the last 15 months respectively. Overall 29% had at least one non-HIV condition of current clinical

concern. HIV services communicated with 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 co-medication. There was variable performance in relation to other outcomes; adherence and laboratory measurements were carried out better than lifestyle and well-being assessment. This approach to a national comparative review of care quality may serve as a model for other country settings, especially where national quality improvement programs are not implemented.

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

Authors: Nadia Ekong[1§], Hilary Curtis[2], Edmund Ong[3], Caroline A Sabin[4], David Chadwick[5], on behalf of the BHIVA Audit and Standards Sub-Committee.

1 Brotherton Wing Clinic, Leeds General Infirmary, United Kingdom
2 British HIV Association, London, United Kingdom
3 Department of Infection & Tropical Medicine, Royal Victoria Infirmary, Newcastle upon Tyne NE1 4LP, UK.
4 Centre for Clinical Research, Epidemiology, Modelling and Evaluation, Institute for Global Health, UCL, London, UK
5 Centre for Clinical Infection, James Cook University Hospital, Middlesbrough, United Kingdom

§ Corresponding author: Nadia Ekong

Brotherton Wing Clinic, Brotherton Wing, Leeds General Infirmary
Great George street, Leeds, LS1 3EX.
01133922944
nadiaekong@nhs.net

E-mail addresses of authors:

NE: nadiaekong@nhs.net

HC: hilary@regordane.net

EO: edmund.ong@newcastle.edu.my

CS : c.sabin@ucl.ac.uk

DC: davidr.chadwick@nhs.net

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Introduction

In 2017, 39% of people seen for HIV care in the UK were aged 50 or over [1]. This proportion is rising as excellent antiretroviral therapy (ART) outcomes continue to contribute to increased life expectancy and increased HIV testing results in more diagnoses in this age group. While welcomed, ageing among people with HIV presents increasing scope for non-HIV related co-morbidity and poly-pharmacy.

Frequently encountered co-morbidities in people with HIV include cardiovascular diseases (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 should not be neglected, especially as mental health problems may have a negative impact on ART adherence. In contrast to the general public, a proportion of people with HIV 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 healthcare contact.

Alongside ART prescribed by HIV clinicians, people with HIV may receive prescribed co-medication 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 immunisations 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 potential for similar methods to facilitate care quality improvement and prevention of non-communicable diseases in people with HIV in high-, middle- and low-income 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 50 and over attending 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, non-routine care, reasons, for example due to 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:

Patient characteristics: gender, age, HIV exposure risk and ethnicity.

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

Medicines management: date when a list of all current medication was last recorded; number of non-ART medications received; whether 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 over the counter (OTC) medication and herbal remedies within the past three years. For individuals with co-prescribed medications, whether it was documented that potential for drug-drug interactions had been considered and pharmaco-kinetics reviewed.

Communication and shared care of co-morbidities: 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 co-morbidities (hypertension, hyperlipidaemia, type 2 diabetes, cardio-vascular disease, 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 co-morbidities of current clinical concern; whether there had been good communication about their management of co-morbidities which were recently diagnosed or of current concern.

Monitoring: dates of last recorded 10-year CVD risk and fracture/bone (FRAX or DEXA) assessments, blood pressure, weight, glucose, lipids 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 co-infected with hepatitis B and/or C, hepatocellular carcinoma (HCC) surveillance. Further questions asked about documentation of the offer of STI screen, menopausal status (women to age 56), annual cervical cytology (women to age 65), 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-July 2018 using LimeSurvey online software (LimeSurvey GmbH, Hamburg, Germany) and analysed in Microsoft® Excel 2010 (Microsoft Corporation, Redmond, Washington USA).

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:

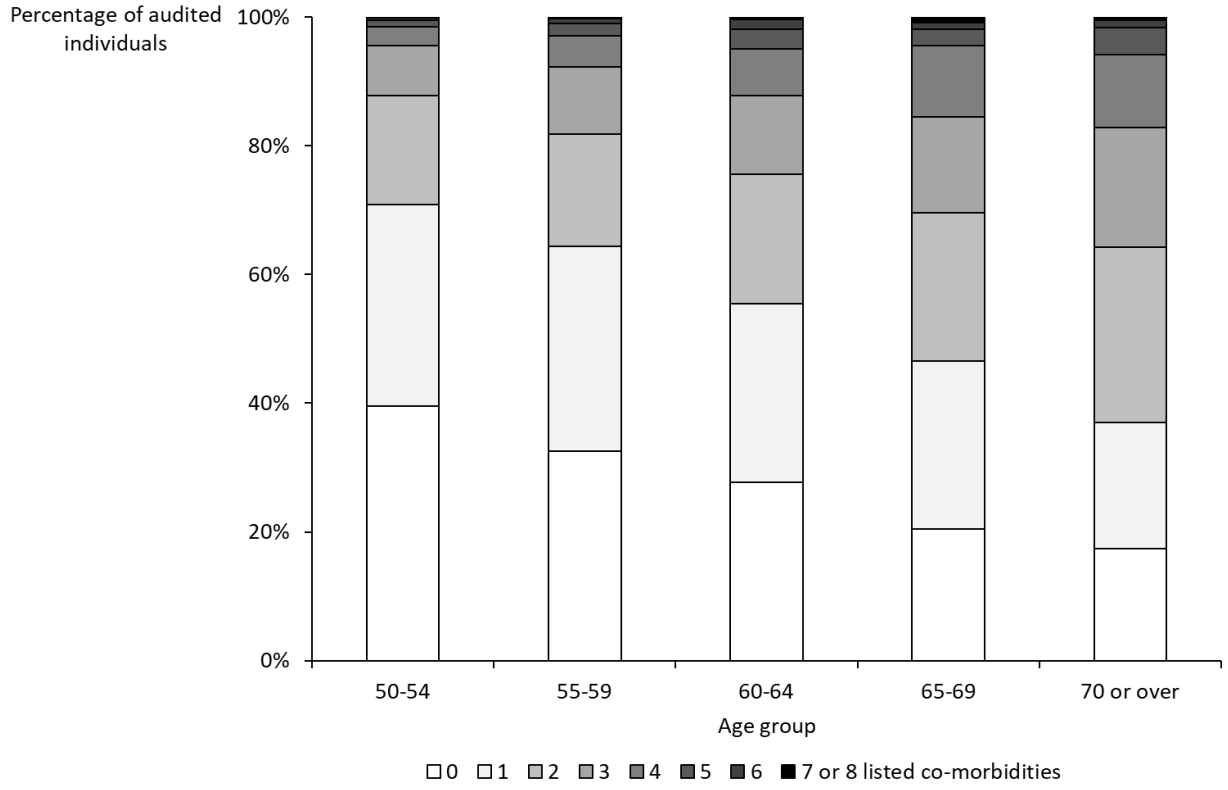
A total of 4959 forms from 141 clinical services were completed. This represents 5% of the 93,385 people reported by Public Health England to be living with HIV and assessing care in the UK in 2017 [16], and 14% of those over 50 years of age (total 36,288) [1]. Three-quarters of individuals were male, over 90% had acquired HIV through a sexual route, two-thirds of individuals were aged 50–59 years old 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 or had newly diagnosed infection. Only 15 (0.3%) individuals had been previously out of care, and information was lacking for 11 (0.2%).

Table 1: Demographics: number (%)

	National
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 (years):	
50-54	1876 (37.8)
55-59	1407 (28.4)
60-64	775 (15.6)
65-69	470 (9.5)
≥70	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)

Significant rates of co-morbidity 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 increased with age (figure 1) with 63% of individuals aged over 70 having at least two listed co-morbidities compared with 37% of those aged 50-54. Overall 29% of individuals had at least one non-HIV 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.

Figure 1: Relationship between age and number of specified listed co-morbidities



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%, inter-quartile range (IQR) 95-100%). All medication had 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) patients having 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.

Table 2: Results of key target outcomes specified in 2016 BHIVA monitoring guidelines

Outcome	No.	%	Target, %	Site median (IQR), %
People on ART (n=4852) with VL measured within last 9 months, or 15 months if on PI	4718	**97.2**	90	97.5 (95.0-100.0)
People on ART (n = 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 diseases, PI: Protease inhibitor, VL: HIV viral load.

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 still room for further improvement especially in relation to CVD.

Table 3: Comparison of 2015 and 2018 BHIVA national review results: key target outcomes

	2015 (age 50+)	2018	P (χ^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%

* Guidelines outcome and target changed: 2015 within 6 months (80%); 2018 within 9 months or 15 if on PI (90%). BP: Blood pressure, CVD: Cardiovascular diseases, VL: HIV viral load.

Recording of other monitoring:

Results of 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 to recording of well-being, life style and fracture/bone assessment.

157

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

	National
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 well-being 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 ≤65, N=1137 nationally)	768 (67.5)
Menopause status recorded (women ≤56, N=739)	511 (69.1)
Immunisation	
Recorded that received/advised about flu vaccine (last season)	1924 (59.6)
Recorded that received pneumococcus vaccine (ever)	1690 (34.1)

160 ART: Antiretroviral therapy, BMI: Body mass index, DEXA: Dual-energy X-ray
161 absorptiometry, FRAX: Fracture risk assessment tool, HbA1c: Glycated Haemoglobin A1c, PN:
162 Partner notification, uP/C: Urine protein creatinine ratio.

163

164 *Medicines management:*

165 Poly-pharmacy increased with age, with the proportion of individuals taking at least four co-
166 prescribed non-ART medications being 24%, 38% and 51% for those in their 50s, 60s and 70s
167 respectively. It was documented that 3423 (69%) individuals had been asked about non-

prescribed OTC medication and 2710 (56%) about herbal or traditional remedies in the preceding 3 years.

Communication and shared care of co-morbidities:

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 and over and accessing HIV care in the UK [1] and revealed high rates of co-morbidity and poly-pharmacy which, as expected, increased with age. The median age of people receiving HIV care is increasing [1-2], and since two thirds of audited individuals were aged 50-59, increasing clinical complexity can be expected with further ageing among people with HIV in the UK. This requires effective evidence-based screening and monitoring as sub-optimal management of co-morbidities and poly-pharmacy can lead to risks of drug toxicity, reduced adherence to life-extending ART, drug-drug 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 poly-pharmacy in the aging HIV 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 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 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 co-morbidities were hypertension and hyperlipidaemia, both of which are CVD risk factors. CVD significantly contributes to non-AIDS morbidity and mortality in people with HIV and has a multi-factorial aetiology involving interplay between traditional risk factors and HIV specific factors like HIV viraemia, immune dysfunction and the pro-inflammatory state associated with HIV infection [2,3,20]. Interventions proven to reduce cardiovascular diseases 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 profile 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.

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 non-communicable 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 non-communicable 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 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 co-morbidities 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 TB co-infection 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 well-being 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 aging HIV population. However the 2018 audit showed some improvement over BHIVA's 2017 national audit in this respect [13], in which psychological well-being/mental health was documented or asked about for only 64% of individuals aged 50 or over.

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 get information about HCC screening in individuals with hepatitis B/C co-infection, 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 Conclusion

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 well-being and lifestyle. In 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 standardised 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 individualised reports enables clinicians to see how their service's outcomes compare with national data, aiding motivation and prioritisation of issues for local quality improvement. While any such approach should be adapted to local needs and circumstances, we believe 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.

Competing interests

HC has no competing interest to declare. NE received travel bursaries from Gilead Sciences and WebEx meeting fee from Merck Sharp & Dohme. ELC Ong has received research funding from Pfizer and Gilead Sciences. CS has received funding for the membership of Data Safety and Monitoring Boards, Advisory Boards and for preparation of educational materials from Gilead Sciences and ViiV Healthcare. DRC has received research funding from ViiV healthcare and lecture fees from Pfizer and Gilead.

Authors' contributions

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

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List of abbreviations

AIDS	Acquired immune deficiency syndrome
ART	Antiretroviral therapy
BHIVA	British HIV association
BMI	Body mass index
BP	Blood pressure
CVD	Cardiovascular diseases
DEXA	Dual-energy X-ray absorptiometry
FRAX	Fracture risk assessment tool
GP	General practitioner
HbA1c	Glycated Haemoglobin A1c
HCC	Hepatocellular carcinoma
HIV	Human immunodeficiency virus
IDU	Injecting drug use
IQR	Inter-quartile range
MSM	Men who have sex with men
NCD	Non-communicable diseases
OTC	Over the counter
PHE	Public Health England
PI	Protease inhibitors
PWH	People with HIV
SCR	Summary care record
uP/C	Urine protein creatinine ratio
VL	Viral load (HIV)

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