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Positive Voices: The National Survey of People Living with HIV

Findings from the 2017 survey

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Ethics approval

This project was reviewed and approved by Health Research Authority and the London Harrow NHS Research Ethics Committee (Project ID 13/LO/0279).

Contents

Abbreviations

A&E: Accident and emergency department
AIDS: Acquired immune deficiency syndrome
ART: Antiretroviral therapy
BMI: Body mass index
COPD: chronic obstructive pulmonary disease
DLA: Disability Living Allowance
EQ-5D-5L: a standardized instrument for measuring generic health status and quality of life introduced by the EuroQol Group (EQ). It has 5 dimensions (5D) - mobility, self-care, usual activities, pain/discomfort, and anxiety/depression and 5 response levels - no problems, slight problems, moderate problems, severe problems and extreme problems.
ESA: Employment and Support Allowance
GHB/GBL: Gamma hydroxybutyrate and gamma-Butyrolactone, also known as G or liquid ecstasy. A drug commonly before or during sex to enhance pleasure and decrease inhibitions (chemsex).
GHQ-12: General Health Questionnaire (GHQ-12) is a validated 12-item psychometric screening tool developed to identify common psychiatric disorders and depressive symptoms.
GP: General practitioner
GUM: Genitourinary medicine
HARS: HIV and AIDS Reporting System
HIV: Human immunodeficiency viruses
HPV: Human papillomavirus
HRQoL: Health-related quality of life
JSA: Jobseeker's Allowance
KS: Kaposi’s sarcoma
LGV: Lymphogranuloma venereum
LTC: Long-term condition
NASS: National Asylum Support Service
NHS: National Health Service
ONS: Office of National Statistics
PIP: Personal Independence Payment
PREMs: Patient-reported experience measures
PTSD: Post-traumatic stress disorder
STI: Sexually transmitted infection
U=U: Undetectable=untransmittable
UK: United Kingdom
UNAIDS: The Joint United Nations Programme on HIV and AIDS

Forewords

It gives us great pleasure to introduce the Positive Voices 2017 report. The journey to get here spans several years of planning, piloting, implementation and analyses. We have worked closely with people living with HIV, academic partners and other key stakeholders to develop a nationally representative survey that captures the complex health and wellbeing of people living with HIV.

There have been phenomenal advances in HIV medicine. Today, HIV treatment is so effective that life expectancy for people with HIV is no different to those without, if people are diagnosed and treated promptly. HIV treatment continues to evolve and for most, consists of taking one pill a day with few or no side-effects. There is also another powerful gain to treatment – it suppresses virus replication so that a person on treatment cannot pass HIV on to sexual partners. This is sometimes referred to U=U (Undetectable=Untransmissable).

Given these medical developments, it should be expected that living with HIV is no different to any other chronic condition. However, Positive Voices paints a more complex picture. Although many people with HIV rate their quality of life highly, overall people with HIV fared worse than the general population in many aspects.

Most live with other health conditions with mental health conditions commonly reported, particularly depression. People with HIV continue to be treated differently and experience HIV-related discrimination, with 1 in 10 avoiding seeking healthcare when they needed it due to fears of stigma. HIV is like no other health condition.

This survey is the first of its kind and a major strength is that we were able to use national HIV surveillance data as a sampling frame to include HIV clinics across England and Wales and ensure participation from people of all backgrounds, making it truly representative of people living with HIV.

Wherever possible the scales and measures used allowed allow us to compare the findings to the general population. Finally, the sheer size of the survey (more than 4,400 people took part – 1 in 20 people living with diagnosed HIV) means that we are able to look at data in great detail and understand whether some people may experience unmet needs for instance.

We thank all of people living with HIV who provide their information for surveillance and research – the information is invaluable in understanding HIV. We particularly thank the people with HIV who completed the survey and who shared their stories to contextualise the Positive Voices findings.

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In February 2017, at regular check-up at my HIV clinic I was asked to fill in the Positive Voices questionnaire. It was a bulky booklet and looked time consuming. But I was also given a £5 voucher, and I had time to spare as I waited for my meds, so I filled it in while sitting in front of the pharmacy.

There were questions on all aspects of my life from experiences of the HIV clinic to more personal stuff, like mental health, loneliness, violence, alcohol and drug use, experiences of stigma and discrimination and finances. I always find these kinds of questionnaires hard, especially if I'm feeling fragile (most people do feel fragile on a dark February morning, during a hospital visit, even a routine check-up). I diligently answered all questions and rewarded myself with a lovely hand cream with my voucher.

Recalling negative experiences can be triggering, and many of us living with HIV have experienced trauma. However, I knew it was important that the life experiences of people with HIV are heard, and that there is so much more to having a good quality of life than just an undetectable viral load.

I was also aware that even without doing much, I have often been the subject of research, as have the other 100,000 people living with HIV in the UK. So much research is done on us, but it is rare that we are actively involved in the process. Positive Voices has been different. Public Health England asked Positively UK, the UK leading peer support organisation together with the National AIDS Trust, to facilitate community ownership and assist with analysis of the Positive Voices data. This project became the Changing Perceptions campaign and reports.

Workshops were held with survey respondents to discuss the findings. Having worked in HIV peer support for 20 years what surprised me was that most people who attended were not our ‘usual’ service users. Many had never used support services or spoken to someone else living with HIV before. Most were compelled to come forward because they wanted to ensure that their lives and experiences mattered, and to help make things better for everyone. There was a clear intention from us all that we did not wish to be solely objects of research. Behind the numbers are lives. We are reclaiming our agency and overcoming notions of victimhood, despite the challenges many still face.

Positive Voices paints a nuanced picture of our lives. From a medical perspective, we are doing well thanks to the excellent HIV care provided by the NHS. However, many of us are struggling: 1 in 8 had not told anyone about their HIV status,1 in 7 experienced discrimination in the NHS in the past year. Mental health problems are reported by half of people living with HIV, around twice that of the general public.

As we listened to each other’s stories and discussed how they illuminated the Positive Voices findings, it was clear that the biggest challenges we face are rooted in negative attitudes and misconceptions around HIV. Peer support is vital for tackling isolation and maintaining well-being, yet it is underfunded and often unavailable.

Positive Voices survey has offered a new clarity about life with HIV in the UK; clarity needed to help people with HIV to stay healthy and have a good quality of life. I’d like to thank the researchers, Public Health England and everyone who completed the survey and made this possible.

www.changingperceptions.co.uk

Silvia Petretti
Chief Executive Officer
Positively UK

Summary findings

The Positive Voices 2017 survey was completed by a representative sample of 4,422 people living with diagnosed HIV infection who were invited to take part through their local HIV clinic between January and September 2017. The survey included 1 in 20 people living with diagnosed HIV in England and Wales.

HIV diagnosis and treatment

More than half (53%) of people with HIV were first diagnosed with HIV in a sexual health clinic. This was highest proportion of those were gay and bisexual men (69%) and the lowest were women (37%). Additionally, 11% were diagnosed by a general practitioner (GP), 11% in a hospital outpatient department, and12% in hospital as inpatients. Amongst women living with HIV, 13% were first diagnosed in pregnancy.

Self-reported adherence to HIV treatment was very high: 89% of people had taken all their HIV tablets in the previous 14 days. A further 6% had only missed one tablet. One in 7 (17%) had side effects to their HIV medication in the previous 4 weeks.

Quality of life, health and well-being

People with HIV reported high ratings on the 3 measures of health and well-being in the survey (self-rated health, life satisfaction, and health-related quality of life [EQ-5D]), reflecting excellent HIV treatment outcomes in the UK. However, compared to the general population, the overall picture showed that people with HIV fared slightly worse across all 3 measures.

Mental ill health was a primary concern among people with HIV, who also experienced a higher burden compared to the general English population. Over 1 in 3 (37%) people with HIV were diagnosed with a clinical mental health disorder in their lifetime. Around half (49%) of people with HIV reported symptoms of depression and anxiety on the day of the survey; much higher than in the general population (30%). One in 4 (28%) had a General Health Questionnaire (GHQ-12) score of 4 or more indicating probable mental ill health at the time they were surveyed, compared to 19% of the general population.

Over half (59%) reported ever having been diagnosed with a long-term condition in addition to their HIV, most commonly high cholesterol, hypertension, arthritis and neuropathy. One in 3 (33%) were living with 2 or more long-term conditions in addition to HIV.

Experience with NHS care and services

Overall, people reported a very positive experience with their HIV care, rating their HIV services on average 9.3 out of 10. No disparity in HIV clinic satisfaction was seen by age, gender, ethnicity, socioeconomic status or across different areas of England and Wales. Agreement with patient-reported experience measures (PREMs) was high: 96% felt supported to self-manage their HIV and 95% felt they were involved in decisions about their HIV treatment and care.

Nearly all (98%) were registered with a GP, and of these, 94% said their GP knew their HIV status. GP satisfaction was lower than HIV clinic satisfaction, with an average rating of 6.9 out of 10. However, this was similar to GP ratings in the general population. Two-thirds (65%) felt that their GP knew enough about HIV and 59% were comfortable asking their GP questions about HIV. One in 5 (20%) did not know whether their HIV doctor and GP communicated about their health.

Sex and relationships

Over half (58%) of people living with HIV had a current main partner. Of those, 57% had HIV negative partners, 39% had HIV positive partners, and 4% did not know their partner's HIV status. People with HIV-negative partners were more likely to use condoms (32% vs 15% of those with HIV-positive partners) and be sexually abstinent (36% vs 25% of those with HIV-positive partners). With over 95% of people with HIV virally suppressed, is suggests not all people with HIV know or believe that having an undetectable viral load means they cannot pass on HIV sexually (undetectable equals untransmittable (U=U)).

One in 3 (36%) of people with HIV had not had sex in previous 3 months; rates of abstinence increased with older age. Most people (94%) reported a close relationship with their partner. However, women were twice as likely to say they were not close to their partners (10%) in comparison to men (5%).

Lifestyle risk behaviours

Body mass index (BMI) calculations indicated that 57% of people with HIV were overweight or obese (BMI≥25), and 1 in 4 (24%) were obese (BMI≥30). Overweight and obesity was highest among people of black African ethnicity; 80% of black African women and 71% of black African men.

Drinking alcohol was common with 73% of people with HIV saying they ever drank alcohol and 49% were regular drinkers (at least weekly). Regular drinking was highest among gay and bisexual men (65%) and lowest among people of black African ethnicity (27%) and women (24%).

One in 5 (20%) were current smokers and a further 28% were ex-smokers. Smoking was highest among gay and bisexual men (26%) and young people aged 18 to 34 years old (30%).

Recreational drug use in the previous 3 months was highest among gay and bisexual men (40%). In this group, the most common drugs used were cannabis (12%), nitrates (8%) and cocaine (7%). Overall, 20% of gay and bisexual men engaged in chemsex in the previous 3 months, and 7% reported slamming (injecting).

Recreational drug use was lower in other groups; 17% of heterosexual men and 5% of women. Use of heroin and crack were rarely reported, at 0.5% and 0.8%, respectively.

Stigma and discrimination

One in 8 (13%) people revealed that they had never told anyone about their HIV status apart from healthcare staff. This proportion was highest among trans people (20%), heterosexual men (19%), people of black African ethnicity (17%) and other minority ethnicities (17%), and women (16%).

Fear of discrimination in healthcare settings was prevalent, with 1 in 6 (16%) of people worried that they would be treated differently because of their HIV status. In the previous year, 1 in 10 (10%) avoided seeking healthcare when they needed it and 1 in 20 (5%) felt that they had been refused or delayed healthcare because of their HIV status.

Housing, Work and Finances

The unemployment rate among people with HIV was 14%, more than triple the 4% unemployment rate in the general UK population during the same period. This is despite people who participated in the survey being highly educated (44% were educated to degree level or higher). Unemployment was highest among trans people (17%), people of black African ethnicity (17%) and other minority ethnicities (14%), women (15%) and younger adults (12% aged 18 to 34 and 12% aged 35 to 44).

The median household income was £20,000 to £29,000 per year. Financial difficulties were common; over half (53%) of those living with HIV did not always have enough money for their basic needs (such as food, rent, gas, electricity) and almost a third (30%) had fallen behind with some or all of their bills. One in 4 (28%) were in receipt of at least one form of means-tested welfare benefit and 15% were in receipt of a disability benefit.

Met and Unmet Needs

One in 6 people with HIV (16%) had contact with an HIV charity or voluntary organisation in the previous year, with a further 22% having had previous contact with these type of support organisations. Despite this, a third of people with HIV (33%) said it had become more difficult to access the support services they needed in the past 2 years.

When people living with HIV were asked about their need for 29 different types of HIV, health and social services in the previous year, the highest level of need was for HIV-related services, such as: 63% needed HIV treatment advice, 49% needed information about living with HIV, 43% needed support managing their long-term conditions and 42% needed adherence support.

Common health-related needs were stress management (33%), psychologist or counsellor (31%), weight management (31%) and help or advice regarding their sex life (27%). The greatest social and welfare needs were for housing support (23%), help dealing with loneliness and isolation (21%) and help claiming benefits (20%).

The greatest unmet need was for help dealing with loneliness and isolation: 75% of those who needed this help did not receive it. Similarly, 69% of the people needing career skills and training and 63% of need for employment advice did not have their needs met. Needs were also unmet for weight management (53%), smoking cessation (48%) and peer support or social contact with other people with HIV (43%).

In contrast, the areas where the needs of people with HIV were mostly met included: HIV treatment advice (93% of need met), HIV treatment adherence support (93% of need met), and information about living with HIV (87% of need met).

Introduction

Public Health England (PHE) is responsible for the national surveillance of HIV, which includes the reporting of new HIV diagnoses and monitoring the clinical outcomes of people accessing HIV care. In 2017, 89,113 people accessed HIV specialist care in England and Wales; 95% of whom were on antiretroviral therapy (ART) and had a suppressed viral load[1]. Successful provision of HIV treatment has reduced the HIV mortality rate; as a result, the cohort of people with HIV is ageing, with 1 in 3 people accessing HIV care now aged over 50 years.

Patient-reported outcomes and experiences are an important part of understanding and monitoring the health and well-being of people with HIV. This knowledge is particularly crucial during a time when significant changes in the delivery of health and social care services are occurring.

Positive Voices is a national cross-sectional probability survey of people living with HIV and accessing care in England and Wales. It aims to identify factors that determine poor health outcomes and disparities among people with HIV. The findings will help inform patient-centred care and tailor the provision of HIV clinical and support services to better meet the needs of people with HIV into the future. This report presents the results of the first Positive Voices 2017 survey.

It followed on from an extensive development phase which started in 2014, consisting of formative research with HIV patients and healthcare staff to develop the survey methodology[2]. The survey was designed in collaboration with an advisory group of clinicians, social scientists, commissioners, survey experts and people living with HIV and was piloted in 30 clinics in 2014[3]. Findings from the pilot study were then used to inform the final survey methodology and questionnaire for the national roll-out in 2017. Details of the Positive Voices 2017 survey methods can be found in Appendix 1.

The 2017 survey covered a range of topics relevant to the lives of people with HIV including: general health and wellbeing, non-HIV health conditions and medications, experiences with healthcare, met and unmet needs, sex and relationships, lifestyle behaviours, and financial security. Wherever possible, validated survey questions and instruments were used to allow comparisons with the general population. All 185 HIV outpatient clinics in England that provided HIV care for at least 10 people with HIV in 2015 were invited between April and June 2016 to be a recruitment site.

The Positive Voices 2017 survey used PHE's national HIV surveillance system, the HIV and AIDS Reporting System (HARS), as a sampling frame to randomly select patients to invite to participate via their HIV clinics. This approach was advantageous for 2 reasons: firstly, random sampling reduced the chance of having a biased group of participants, and secondly, the survey data could be linked to clinical data in surveillance records. This linkage provided an opportunity to study the relationship between patient-reported needs and experiences with their clinical information (for example, attendance patterns, treatment and viral suppression). Ensuring patient confidentiality throughout the project was paramount. No names or other patient identifiable information were collected in the Positive Voices 2017 survey and anonymity was maintained by using pre-generated Positive Voices survey identifiers.

To date, the Positive Voices 2017 survey is the largest survey of people living with HIV in England and Wales, and has been successful largely because of the flexible, iterative approach and engagement of community and civil society organisations, clinicians, academics and commissioners. The survey was designed to be integrated as part of the routine national HIV surveillance in the United Kingdom (UK) and run at regular intervals with the next survey planned for 2021.

Data tables accompany this report can be found at: www.gov.uk/hiv-positive-voices-survey

In 2018, a series of 3 community-led reports, Changing Perceptions, were co-produced alongside people living with HIV who took part in the Positive Voices 2017 survey and in collaboration with Positively UK and National AIDS Trust and can be found at www.changingperceptions.co.uk

- HIV and our needs www.changingperceptions.co.uk/hiv-and-our-needs
- HIV and attitudes www.changingperceptions.co.uk/hiv-and-attitudes
- HIV and our relationships www.changingperceptions.co.uk/hiv-and-our-relationships

Positive Voices survey participants

Between January and September 2017, people living with diagnosed HIV infection were randomly sampled from 73 HIV clinics across England and Wales (Figure 1) and invited to take part in the Positive Voices survey. In total, 4,422 people living with diagnosed HIV completed the survey representing approximately 1 in 20 (5.3%) people living with diagnosed HIV in England and Wales. The data presented in this section are unweighted counts and percentages of the demographic characteristics of the Positive Voices 2017 survey participants.

Figure 1: Location of Positive Voices 2017 participating HIV clinics in England and Wales

Of participants, 71% (3,110/4,361[i]) were men, 27% (1,208) were women (including transwomen). A total of 39 (0.9%) persons identified as trans, which included 15 (0.3%) people who were assigned a different gender at birth (all currently identified as women), 19 (0.4%) who identified their gender as non-binary and 5 (0.1%) who identified their gender in another way. No transmen completed the survey[ii].

With regards to sexual orientation, 70% (2,112/3,000) of men identified as gay, 22% (651) as heterosexual and 5% (152) as bisexual. Among women, 94%, (1,052/1,114) identified as heterosexual, 2% (22) as bisexual, and 0.4% (5) as lesbian. Forty-one (1.4%) men and 10 (0.9%) women identified as asexual or in another way.

The age of participants ranged from 18 to 85 years with a median age of 48 years. On average, people had been living with their HIV diagnosis for 12.5 years (range 2 to 36

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[i] Denominators may be less than the total number of participants due to missing data

[ii] Note on gender: where binary gender breakdowns are presented, trans people were included in the gender groups with which they self-identified. Due to small numbers those who identified as non-binary or in another way (representing 0.5% of Positive Voices respondents) were excluded.

years, median 11 years). The earliest year of diagnosis was 1981, with 13% (545/4,287) diagnosed in the pre-highly active ART era (1995 or earlier). The latest year of diagnosis was 2015[iii].

Half of participants (51%, 2,201/4,357) identified as being of white British/Irish ethnicity, 27% (1,156) black African, 10% (424) other white background, 3% (126) black Caribbean, 1% (54) other black background, 3% (149) of mixed ethnic background, 3% (140) Asian, 1% (62) Hispanic/Latino, and 1% (45) other ethnicities. Just over half of participants (52%, 2,197/4,265) were UK-born, 29% (1,226) African born, 10% (436) European born, and 10% (406) born in Americas, Asia, or Oceania.

Most participants resided in urban areas (88%; 3,556/4,052), based on ONS rural/urban classifications[4]. Half of participants (49%; 2,146) lived in London, 16% (698) lived in the North of England, 16% (693) lived in the South of England, 11% (477) in the Midlands, 8% (339) in the East of England, and 2% (69) in Wales.

Overall, 62% (2,610/4,241) of participants reported being religious, 9% (375) were spiritual, but not religious, and 30% (1,256) were atheist or agnostic. The most common religion reported was Christianity, reported by 85% (2,210) of those with a religion and 53% of all participants. Among religious participants, 48% felt their religion was very important, 26% fairly important, and 26% felt religion was not important in their lives.

The educational attainment of survey respondents was high, with 94% (3,842/4,109) completing education to secondary school level (to age 18 years). Ten percent (10%, 410) held further technical or vocational qualifications, 28% (1,167) held bachelor’s degrees or equivalent, and 16% (662) held post-graduate degrees. Overall, 45% of people with HIV were educated to degree level or above. Educational attainment was highest among people born abroad (48% compared to 40% of those who were UK-born), men (46% compared to 42% of women and 36% of trans people), and younger adults aged 18 to 34 years (48% compared to 36% of those aged 65 and older).

Representativeness and weighting of the Positive Voices 2017 sample

The demographic profile of the Positive Voices 2017 survey respondents was compared to national HIV surveillance records of all people accessing HIV care in 2017 for gender, age, ethnicity, area of residence and treatment status (Figure 2).

The demographic profile was similar (±5%) for all demographics compared, but slightly overrepresented older white men and Londoners. To adjust for these small differences and ensure the estimates in this report were representative of the population accessing

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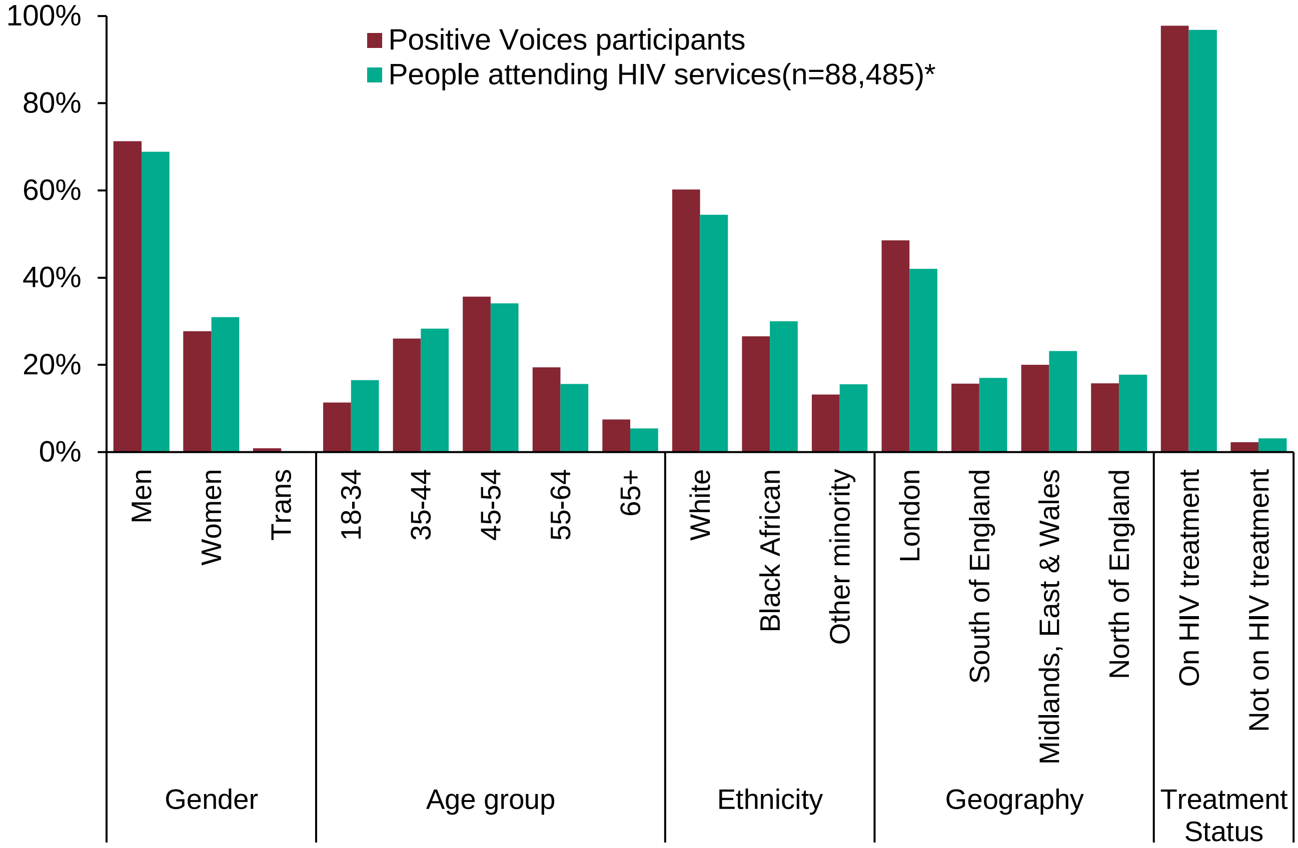
[iii] This is due to the study design, where potential participants were sampled from a list of patients who attended HIV services in 2015, which was the most recent data as of January 2017.

HIV care in England and Wales, the survey data were weighted to conform to that demographic profile.

Figure 2: Representativeness of Positive Voices participants compared to all people accessing HIV care in 2017



*Source: HIV/AIDS Reporting System (HARS): 2017 HIV clinic attendees, aged ≥18, resident in England or Wales

A weighting algorithm based on gender, ethnicity, HIV risk group, age and residence has been applied to all the analyses that follow. Consequently, the findings in the rest of the report are weighted and presented in terms of sample percentages rather than frequencies.

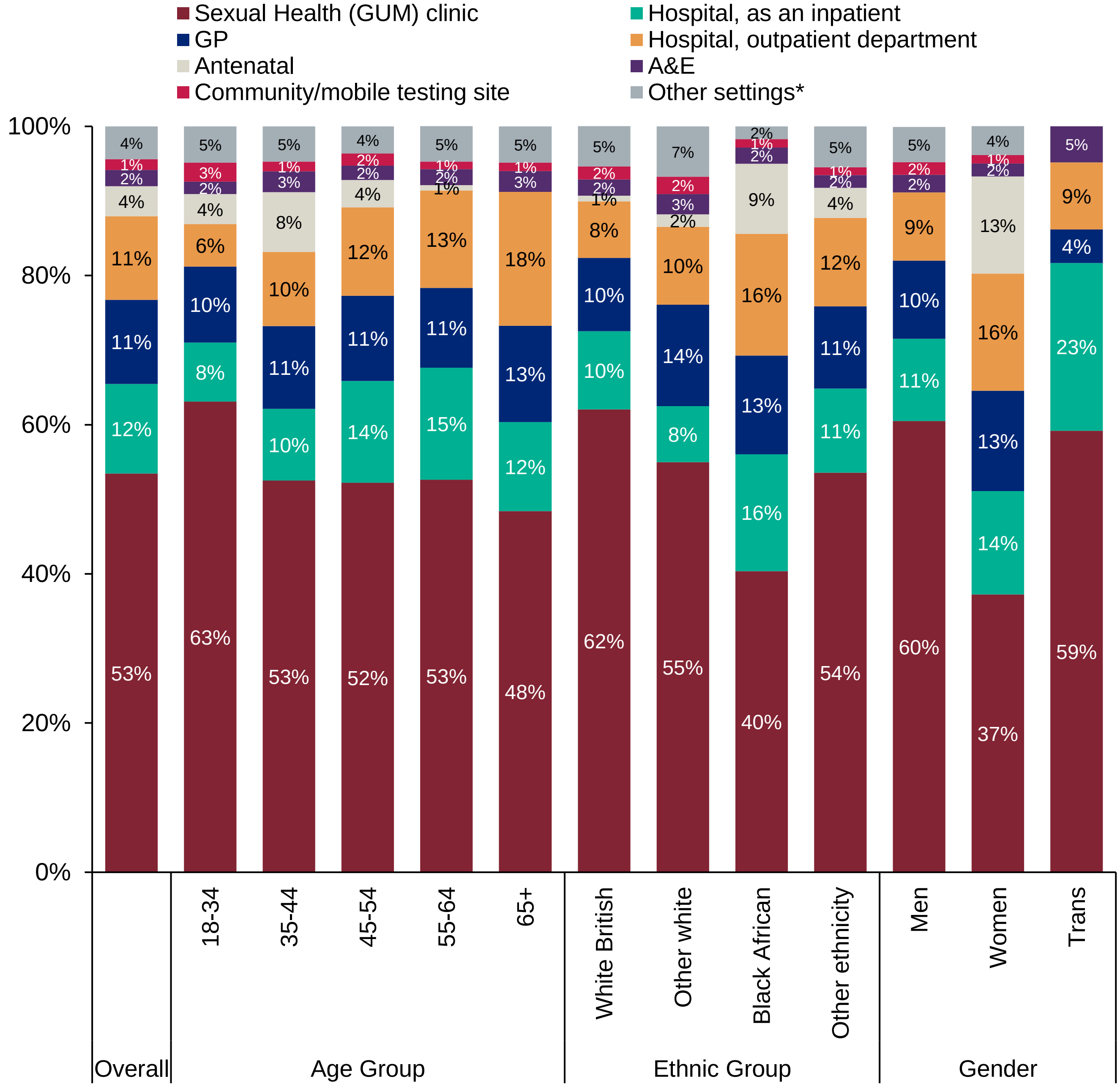
See the Appendix for a full description of the weighting algorithm and the survey methodology.

HIV diagnosis and treatment

Setting of first HIV diagnosis

Overall, 89% of people with HIV in England and Wales were first diagnosed with HIV in the UK. One in 5 (20%) European-born people had been first diagnosed with HIV in Europe, compared to 1 in 13 (8%) of African-born people who had been first diagnosed with HIV in Africa.

Figure 3: Setting of first HIV diagnosis by age and ethnicity and gender



*Includes drug services, prison, blood donation, HIV self-tests, self-sampling kits, and any other setting

The setting where people first tested positive for HIV varied widely (Figure 3). Over half (53%) of people with HIV were first diagnosed in a sexual health clinic. Eleven percent of people with HIV were first diagnosed with HIV by a GP. The same proportion (11%) were first diagnosed in a hospital outpatient department and 12% were diagnosed while in hospital as an inpatient. Among women,13% were diagnosed in pregnancy. Nearly two-thirds of women (63%) were diagnosed outside a sexual health clinic (including antenatally), compared to one-third of gay and bisexual men (31%).

HIV treatment adherence and side effects

Almost all (98%) people with HIV were currently taking ART, with an average of 2 tablets taken per day (range 1 to 16). More than a third (36%) were on a single tablet HIV treatment regimen, 31% took 2 tablets, 24% took 3 tablets, and 10% took 4 or more tablets per day.

Self-reported adherence to HIV treatment was very high, with 89% reporting that they had taken all their HIV tablets in the previous 14 days. A further 6% had missed only one tablet.

One in 6 people on ART (17%) reported side effects to their HIV medication in the previous 4 weeks. On a scale ranging from 0 (not bothered at all) to 10 (extremely bothered), people with HIV rated their side effects on average 5.3 out of 10.

> “If it wasn’t for a peer support member, I would have never known that one of the side effects which had drastically affected my life since I went on medication, were caused from one tablet, which when mentioned to my HIV consultant, resulted in a change of medication and a drastic improvement to my quality of life.” Johan[iv], 41

[iv] Names are fictional and for descriptive purposes only. Quotes are from Positive Voices survey participants.

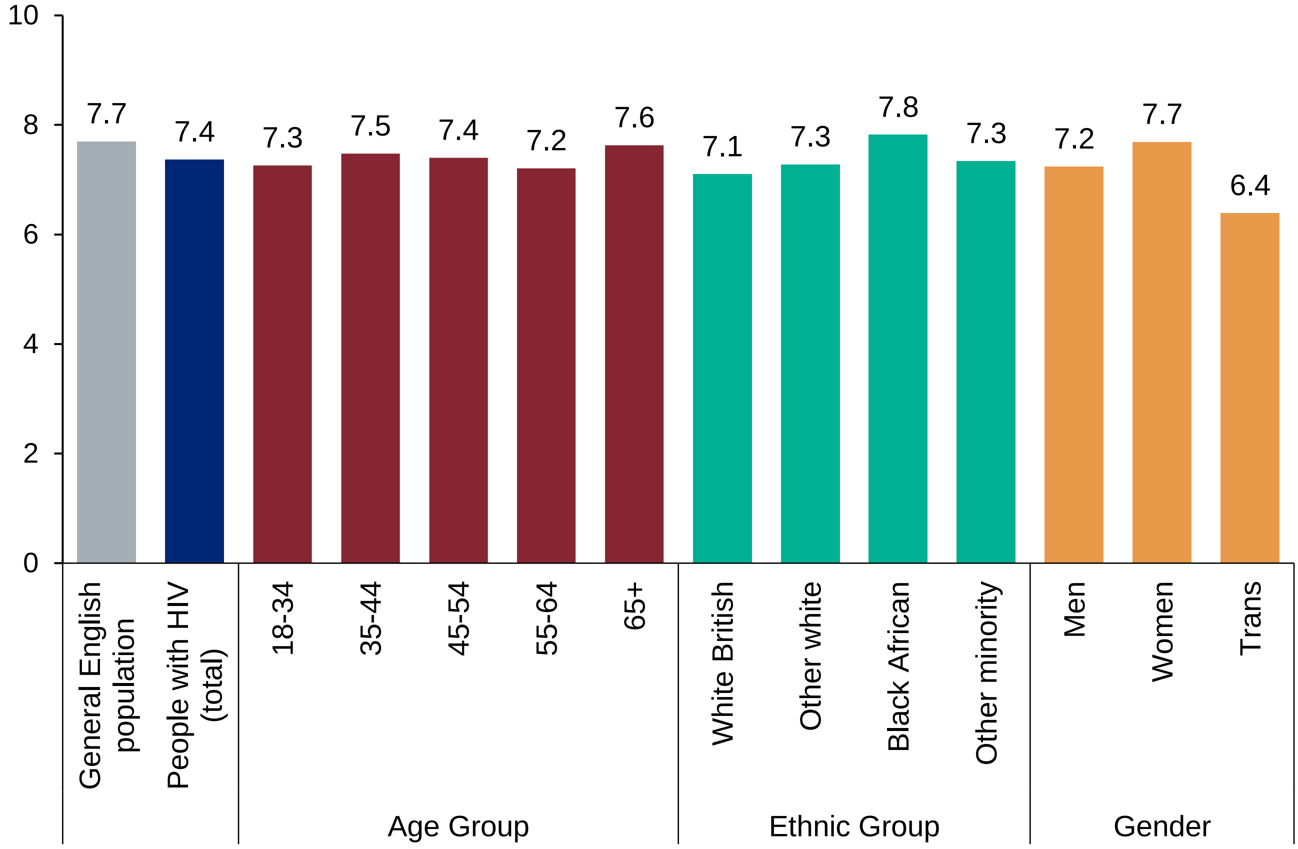
Quality of life, health and well-being

> “Once you are diagnosed with HIV, your self-esteem goes down, your activities decline, and I feel that you really need psychological, social and spiritual support for your well-being. If you cannot work fully, how are you going to survive?”
> Lindwe, 55

Life satisfaction

People with HIV rated their satisfaction with life nowadays, on a scale of 0 to 10 where zero was “not satisfied at all” and 10 was “completely satisfied.” The average life satisfaction score was 7.4, compared to 7.7 in the general population in England[5]. Life satisfaction ratings were similar across age, gender or ethnicity groups; however, trans populations reported the lowest life satisfaction ratings (6.4 out of 10) (Figure 4).

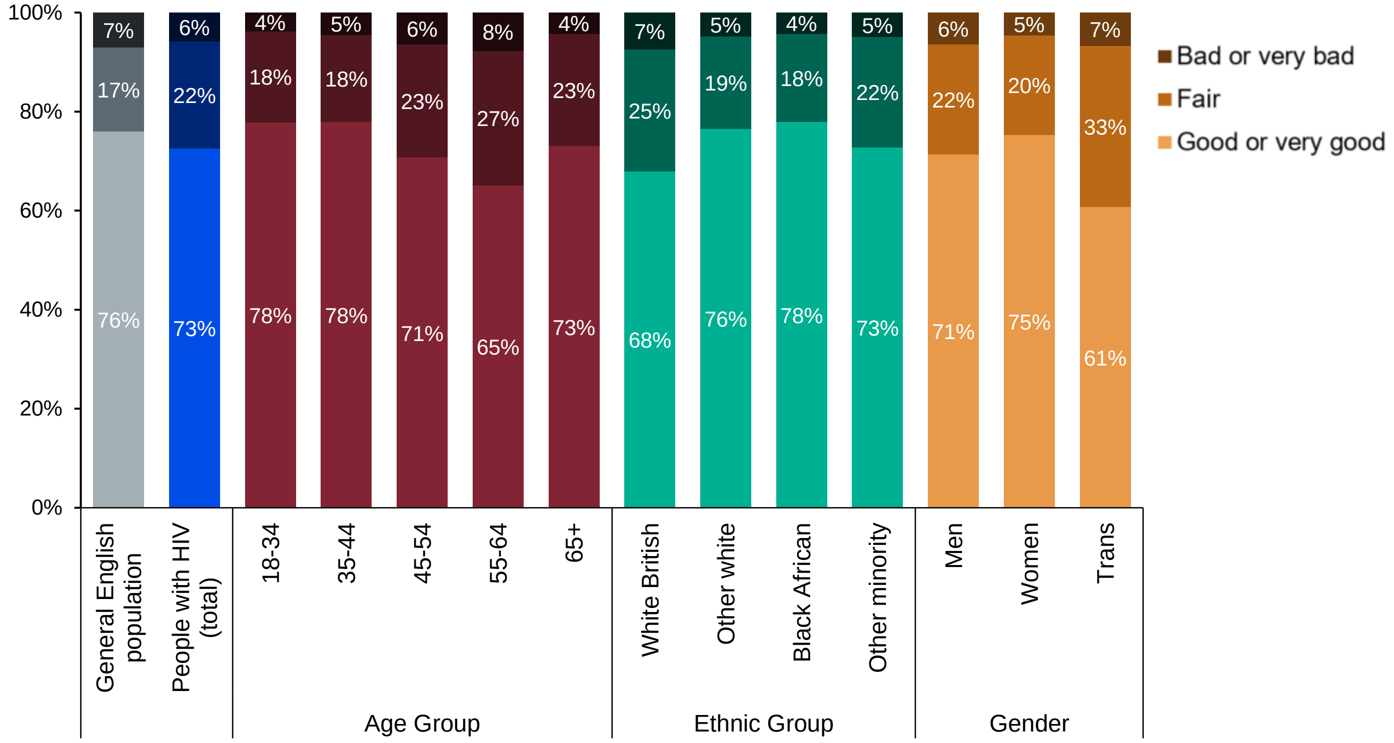
Figure 4: Average life satisfaction rating (scale of 0-10) of people with HIV by age, ethnicity and gender and compared to the general English population



Self-rated health

People were asked to rate their general health on the day that completed the survey. Nearly three-quarters (73%) rated their health as “Good” or “Very good”, compared to 76% of the general population in England (Figure 5)[6].

Figure 5: Self-rated health of people with HIV by age, ethnicity and gender and compared to the general English population

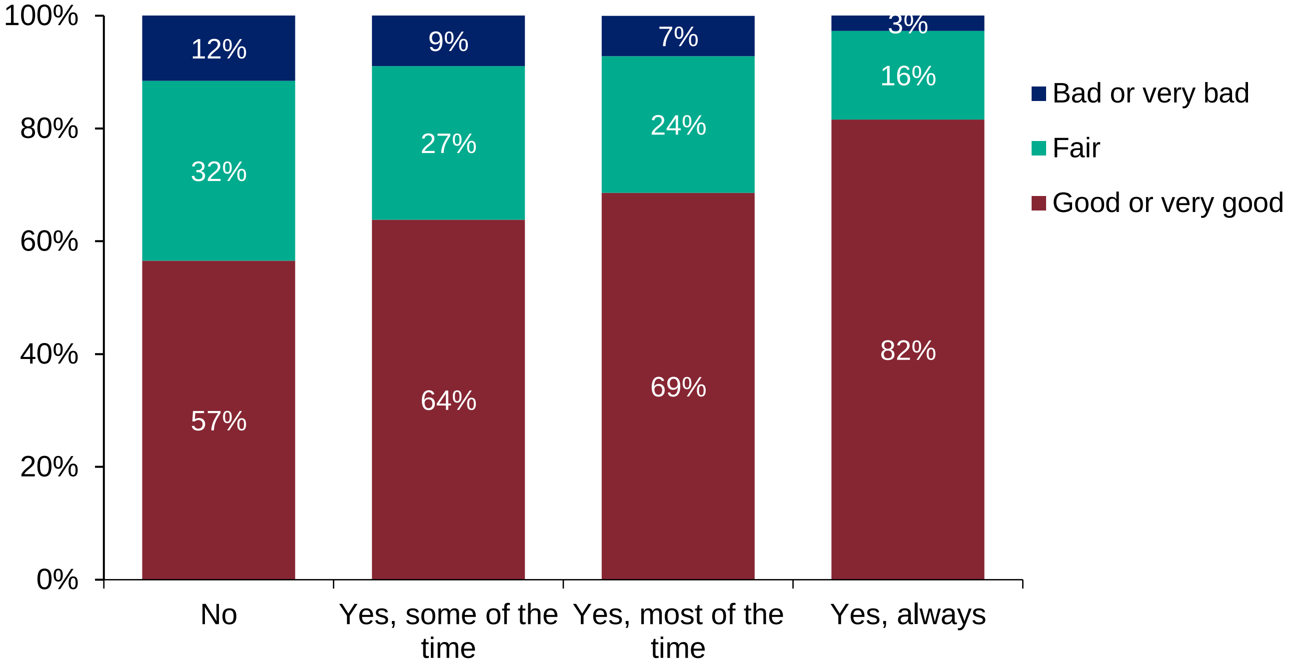


There was variation between demographic groups, with the best health ratings given by younger adults aged between 18 to 44 (78%), black Africans (76%), people of other white ethnicity (76%), and women (75%).

Poverty is generally an important predictor of poor health and this was reflected in people with HIV, who rated their health much worse when they also did not have enough money to meet their basic needs. Overall, 12% rated their health as “Bad” or “Very bad” if they did not have enough money to meet their basic needs, compared to 3% of those who always had enough money (Figure 6).

> “Due to the way I work I don't have time off. I work 6 days a week - that's 4 days plus 2 days overtime or all week so as to earn more to help me pay bills so my health is being affected.” Patricia, 54

Figure 6: Self-rated health of people with HIV by whether they had enough money to afford their basic needs



Health-related quality of life (EQ-5D-5L)

Health-related quality of life (HRQoL) is a multi-dimensional concept of how a person's perceived health relates to their general well-being and quality of life. The survey included a standardised HRQoL instrument, EuroQol (EQ-5D-5L). EQ-5D-5L is a generic (ie. not HIV specific) questionnaire that asks participants to indicate problems or symptoms relating to 5 'domains' of physical and mental health:

- mobility
- self-care (washing and dressing)
- ability to do usual activities (work, study, housework, family or leisure activities)
- pain and discomfort
- anxiety and depression

People with HIV were asked to consider their feelings on the day they completed the survey and to select one of 5 options: starting with no problems or symptoms, and progressing to slight, moderate, severe and extreme problems or symptoms. These responses gave a 5-digit number which described their health state. These health states were transformed using a standardised value set for England[7], to produce an overall HRQoL score (also known as a 'utility score') which ranged from 0 to 1, where 0 represents a state worse than death and 1 represents the best possible health. The data were compared to the general population in England using data from the Health Survey for England 2017 provided on request from NHS Digital. Utility scores were calculated using the same value set[8].

Figure 7: Proportion of people with HIV reporting any problems for each of the 5 EQ-5D-5L domains, compared to the general English population

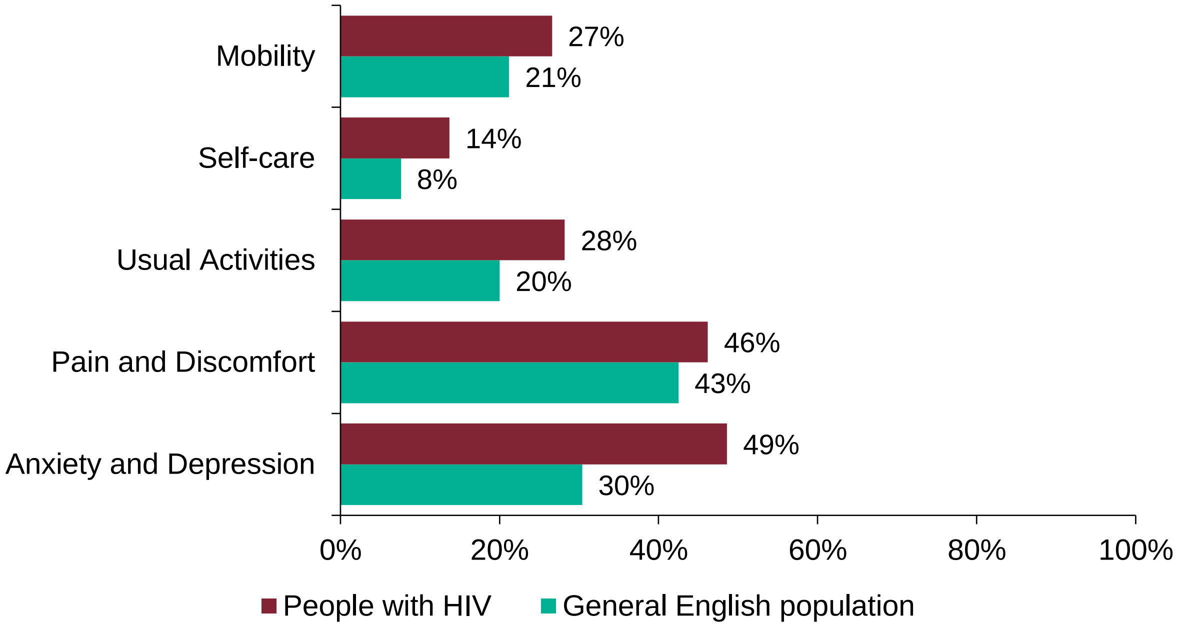


Figure 7 shows the proportion of people with HIV who indicated any problems for each of the 5 EQ-5D-5L domains, compared to the general population in England. People with HIV performed worse across all 5 domains compared to the general population, despite being younger in comparison.

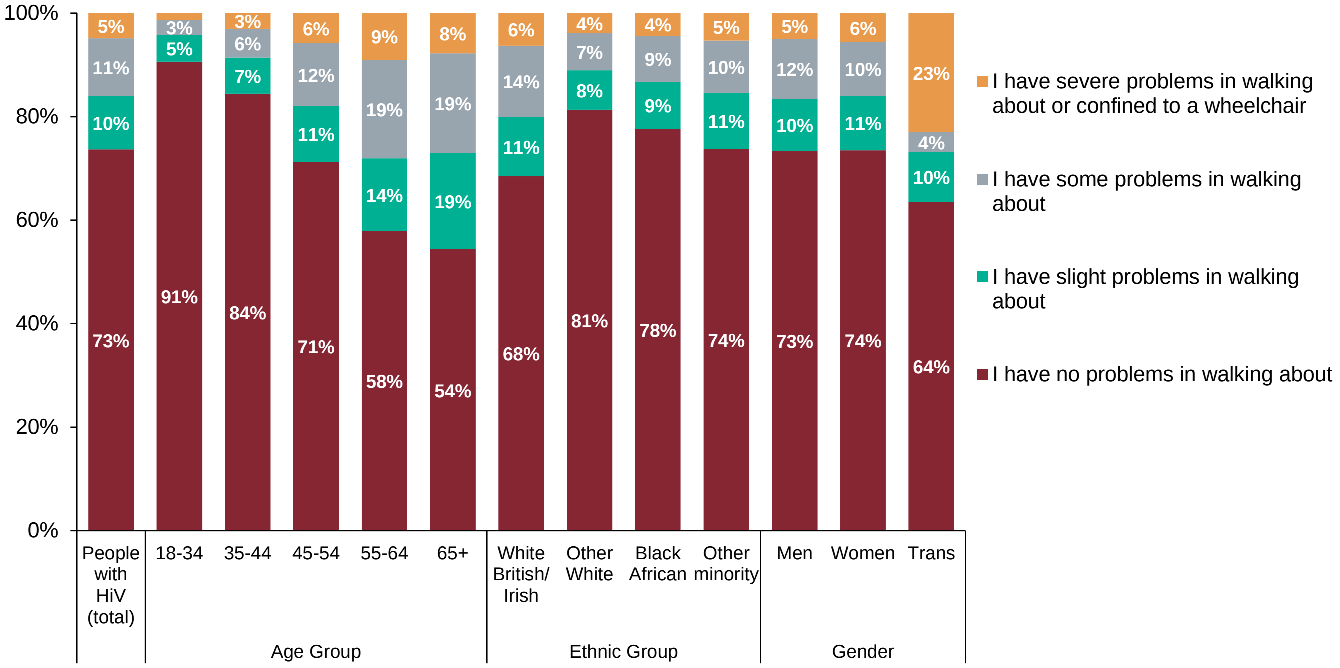
The greatest disparity was seen for anxiety and depression symptoms, with 49% of people with HIV reporting symptoms compared to 30% of the general population in England. Almost 3 times as many people with HIV reported severe or extreme anxiety and depression (9%) compared to the general population (3%).

Pain was also common, with almost half (46%) of people with HIV reporting pain and discomfort on the day of the survey. One in 10 (10%) had severe or extreme pain and discomfort: twice as many as the general population (5%). One in 20 (5%) reported severe mobility problems or were confined to a wheelchair, and 6% either had severe problems doing usual activities or were unable to do them.

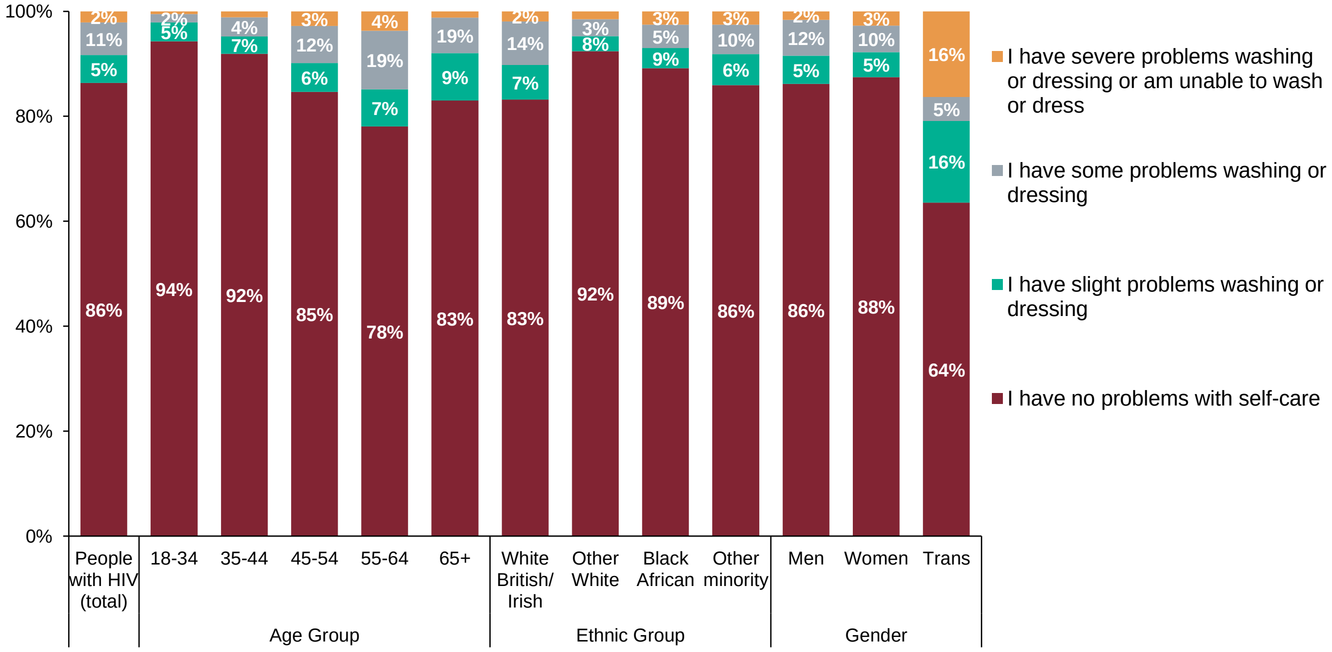
Figure 8a-e shows the distribution of responses for each of the 5 EQ-5D-5L domains, by age, ethnicity and gender. The distribution of problems reported by people with HIV varied widely between the various groups; older adults and trans people consistently reported worse problems. Women reported more pain and discomfort (50% vs 45% of men), whereas men reported more anxiety and depression (52% vs 41% of women).

Figure 8: Distribution of the 5 EQ-5D-5L domains among people with HIV by age, ethnicity and gender

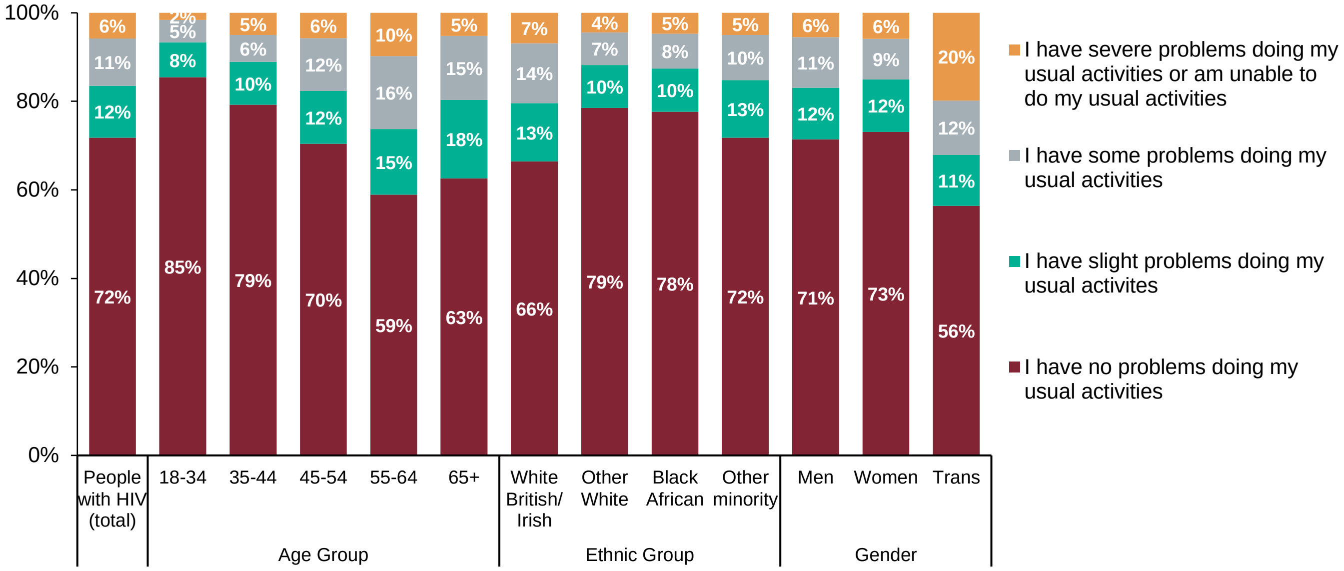
a) Mobility



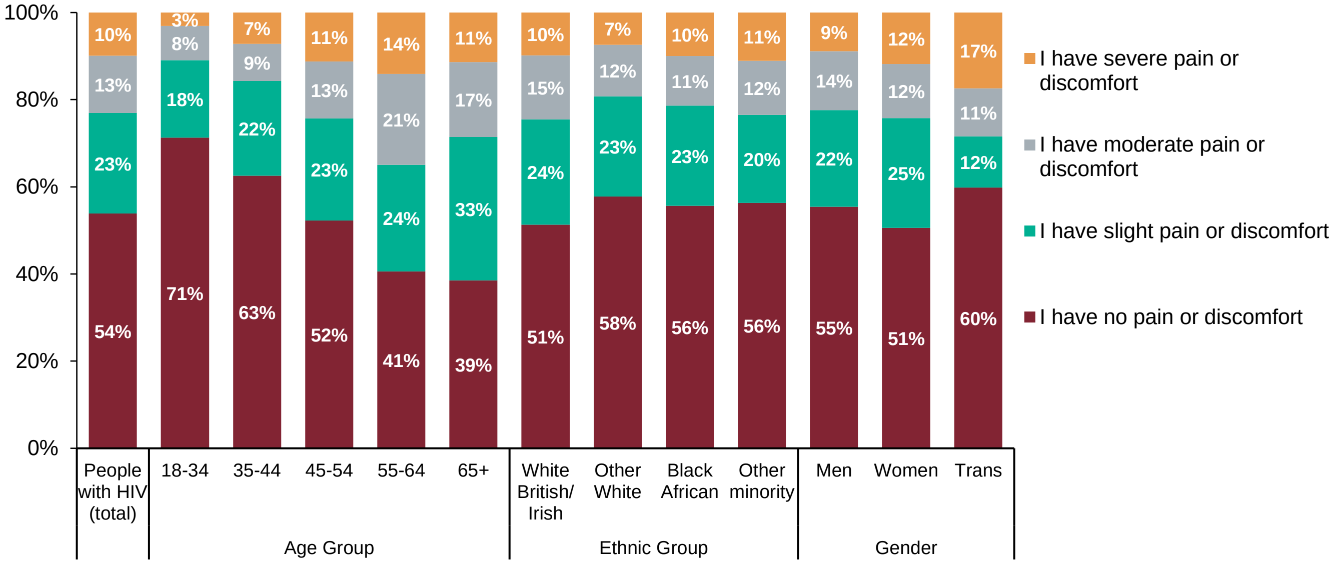
b) Self-care (washing and dressing)



c) Ability to do usual activities (work, study, housework, family or leisure activities)



d) Pain and discomfort



e) Anxiety and depression

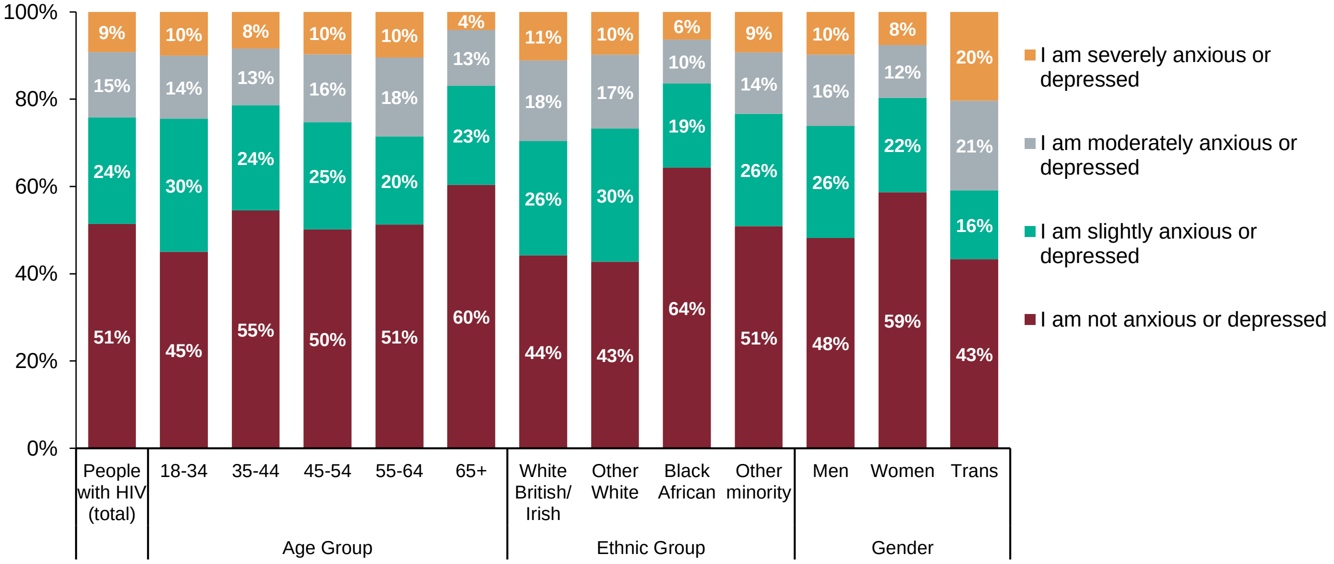
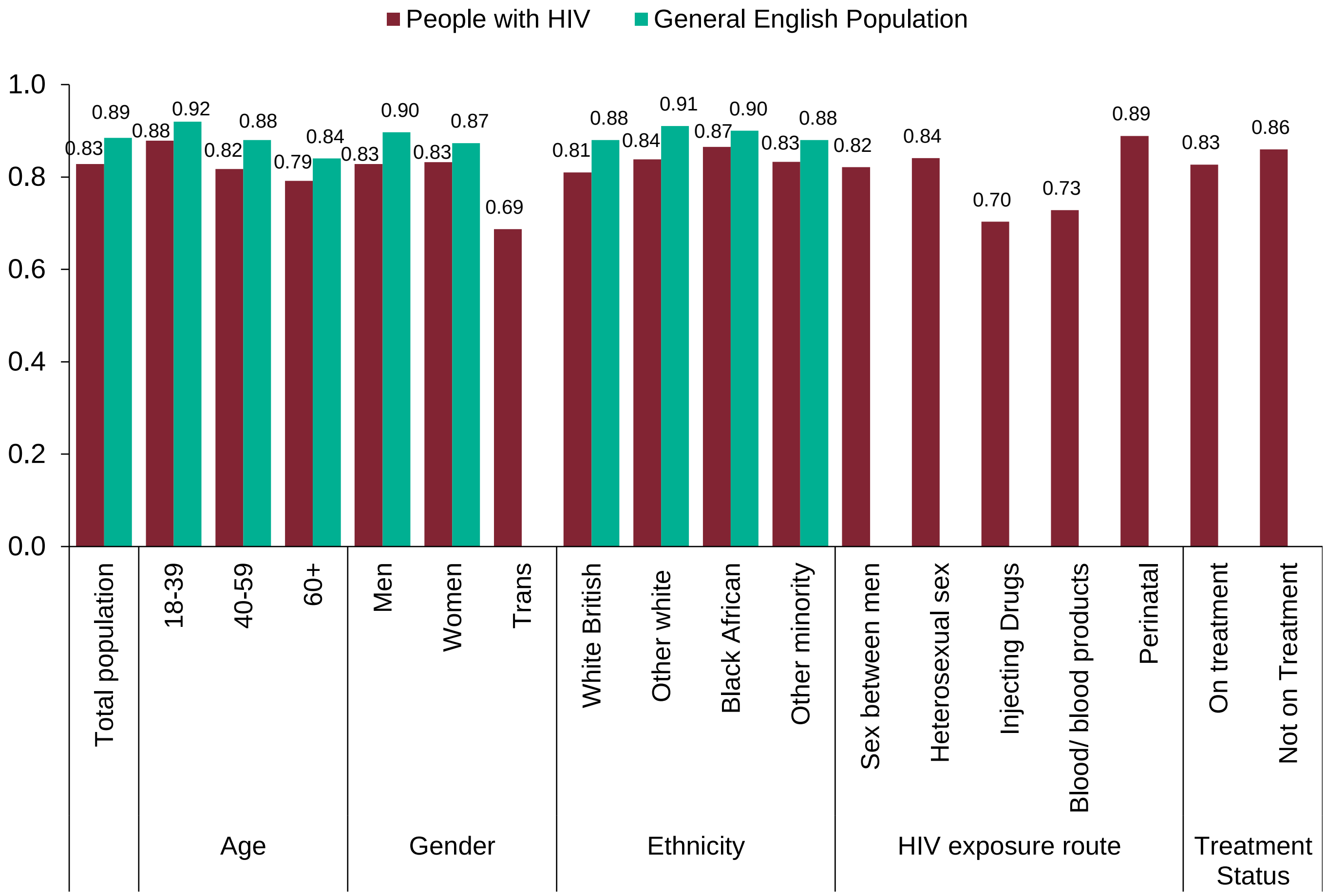


Figure 9 shows the overall HRQoL score (EQ-5D-5L utility score) for people with HIV compared to the general population in England. People with HIV had an average score of 0.83, on a scale of 0 to 1; slightly lower than the general English population at 0.89.

Again, people with HIV had worse HRQoL scores across all demographic groups in comparison to their counterparts in the general English population. Young people (aged 18 to 39) and those infected vertically (these groups intersect) were the only groups with an HRQoL comparable to the general population, at 0.88 and 0.89 respectively.

The groups with the lowest HRQoL scores were trans people with HIV (0.69), people who acquired HIV through injecting drug use (0.70), and blood or blood products (0.73), and people with HIV aged 60 and older (0.79).

Figure 9: Health-related quality of life (EQ-5D-5L) scores for people with HIV, by demographic factors[v] and compared to the general English population[vi]



> “Now that medication and treatment are very effective, psychological well-being is the bigger battle in an HIV diagnosis, because of stigma from the way HIV was portrayed in the past... It’s easy to feel depressed.” Angelique, 49

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[v] Exposure route and treatment status from clinician reports in the HIV/AIDS Reporting System (HARS)

[vi] Data available for age, gender and ethnicity only

Mental health symptoms (GHQ-12)

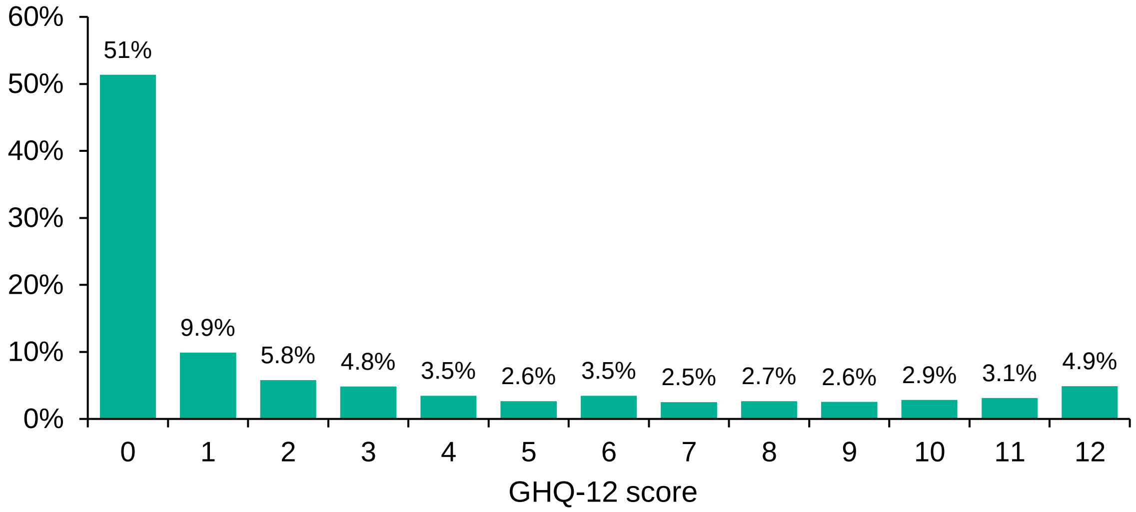
Mental health symptoms were assessed using the General Health Questionnaire (GHQ-12), a 12-item validated instrument used to screen for minor psychiatric disorders which is widely used in public health research and population surveys. GHQ-12 assesses general levels of happiness, depression, anxiety, sleep disturbance and self-confidence. The GHQ-12 is scored on a range from 0 to 12, and grouped in 3 categories:

- **Score 0:** no mental health symptoms
- **Score 1 to 3:** mild mental health symptoms
- **Score 4 or more:** probable mental ill health

Health Survey for England last measured GHQ-12 in 2016 and these data were used for comparison. The same scoring and thresholds were applied to the Positive Voices data, to make meaningful comparisons between the general population in England and people with HIV.

More than half (51%) of people with HIV had a GHQ-12 score of 0, 21% had a score of 1 to 3, and 28% had a score of 4 or more. One in 20 (5%) gave the highest possible score of 12. The distribution of GHQ-12 scores is shown in Figure 10.

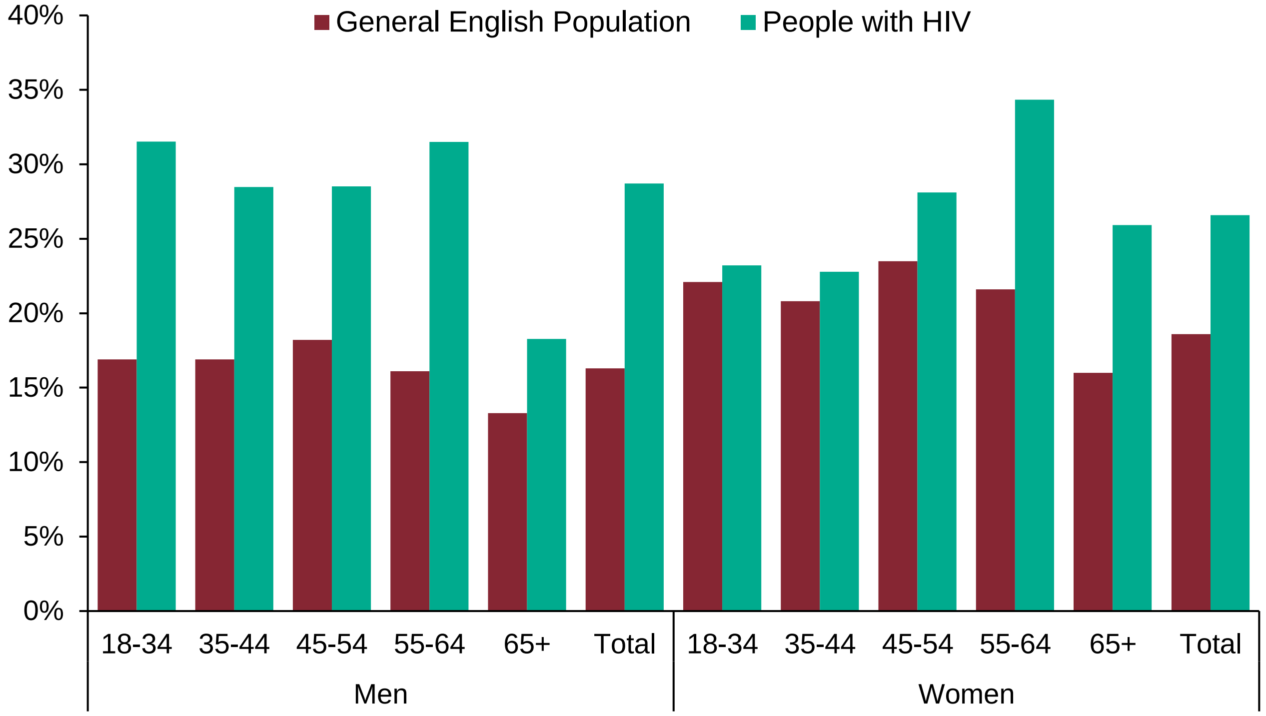
Figure 10: Distribution of GHQ-12 scores in people living with HIV



The proportion of people with HIV who reported symptoms of mental ill health (GHQ-12 score of 4 or more) was 28% compared to 19% in the general population[9]. Figure 11 shows a comparison to the general population in England. Across all gender and age groups, prevalence of mental ill health was higher among people with HIV.

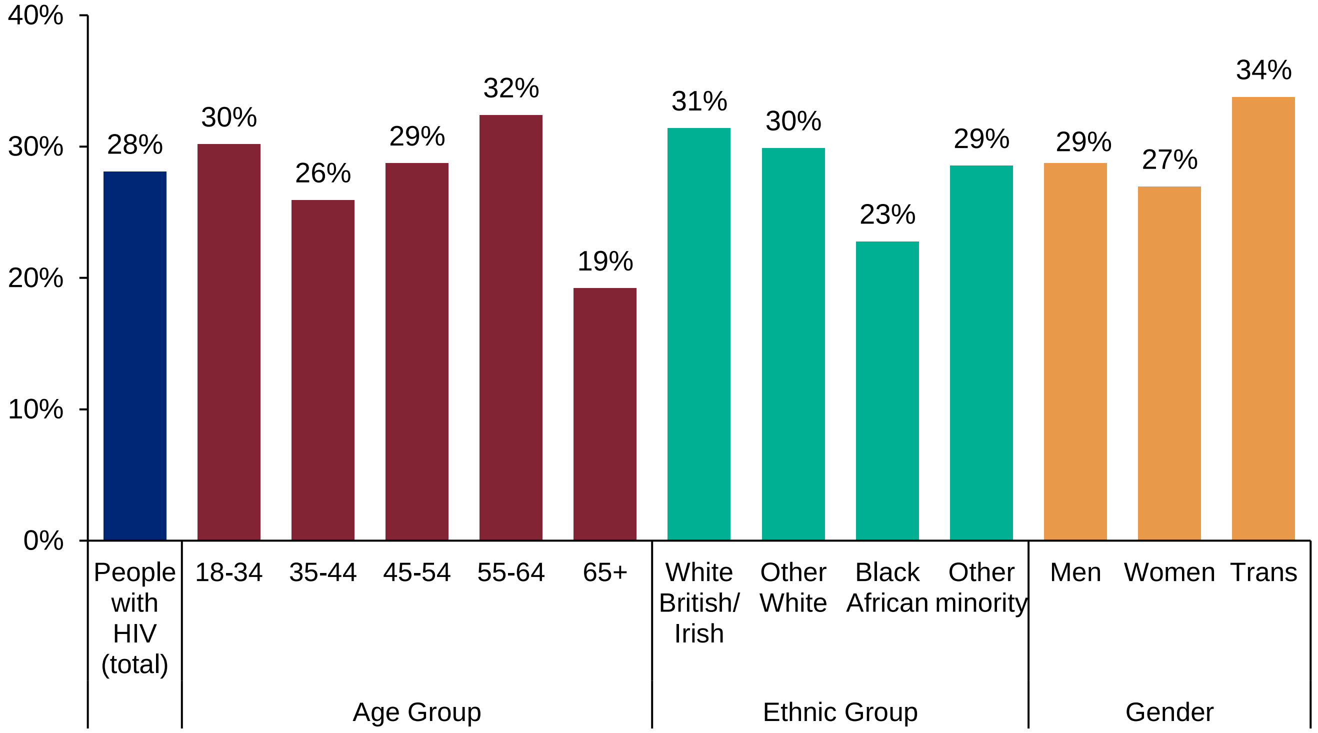
Men with HIV were more likely to have a GHQ-12 score of 4 or more (29%) in comparison to women with HIV (27%); opposite to the general population. This was driven by a higher prevalence of mental ill health among younger men (aged 18 to 44) compared to women of the same age; again, in contrast to the general population.

Figure 11: Proportion of people with HIV with symptoms of mental ill health (GHQ-12 score 4 or more) compared to the general English population, by gender and age group



Among the HIV population, there was variation in GHQ-12 scores (Figure 12). Prevalence of mental ill health symptoms was highest among people of white ethnicity and trans people. There was no clear trend in mental health symptoms by age.

Figure 12: Proportion of people living with HIV reporting symptoms of mental ill health (GHQ-12 score of 4 or more), by age, ethnicity and gender



Health conditions and medications

The presence of health conditions alongside HIV can complicate clinical care with issues such as polypharmacy and contraindicated medication. To assess prevalence of non-HIV related health conditions, people with HIV were asked to self-report if they had ever been clinically diagnosed from a list of 24 different medical conditions (Table 1).

Table 1: Medical conditions included in questionnaire

Cardiovascular conditions	Diabetes High cholesterol High blood pressure (hypertension) Heart attack Stroke or mini-stroke
Joint and bone conditions	Rheumatoid arthritis Osteopenia/osteoporosis Arthritis
Cancers	Type specified by participant[vii]
Other long-term medical conditions	Asthma Chronic obstructive pulmonary disease (COPD) Erectile dysfunction Kidney (renal) disease Neuropathy/peripheral neuropathy Dementia Epilepsy (seizures) Sleep disorder/insomnia
Mental health disorders	Anxiety Depression (including post-natal) Personality disorder Bipolar disorder Eating disorder Post-traumatic stress disorder (PTSD) Psychosis or schizophrenia
Viral infections	Hepatitis B Hepatitis C Genital herpes (including vaginal and anal) Genital warts (human papillomavirus (HPV))

Space was left for participants to write in rarer conditions and these were validated as ‘long-term conditions’ by 2 independent clinicians (see Appendix for further details). Prescribed medication use in the previous 4 weeks was also collected.

[vii] Excluding basal cell carcinoma and abnormal (pre-cancerous) lesions or cells

Long-term health conditions and multi-morbidity

Long-term conditions (LTC), or chronic diseases, are conditions for which there is no cure but symptoms can be managed with drugs and other treatment, such as high cholesterol, diabetes, asthma and arthritis. Mental health conditions, or mental disorders, are psychological syndromes that affect behaviour and mental well-being and can cause significant distress and loss of function. Mental disorders may present as acute or chronic with varying severities, but, like other LTCs, there are no cures for mental disorders, but they can be managed with treatment.

Three in 5 people with HIV (59%) had ever been diagnosed with another LTC in addition to HIV (Table 2)[viii]. By the age of 45, half of people with HIV were living with a diagnosed LTC. As in the general population, LTCs were more prevalent in older people with HIV (82% in those aged 55 and older compared to 32% of those aged 18 to 34 years).

In contrast, the prevalence of diagnosed mental disorders among people living with HIV was similar across age groups. Overall, 37% had ever been diagnosed with a mental disorder, which included common disorders like depression and anxiety, as well as more severe mental disorders like bipolar disorder or post-traumatic stress disorder (PTSD). Trans people (53%), people of white ethnicity (46%), and men (39%) were more likely to have a diagnosed mental disorder.

Table 2: Prevalence of diagnosed long-term health conditions in people living with HIV

	People with HIV (total)	Age Group			Ethnic Group			Gender		
		18-34	35-54	55+	White	Black African	Other minority	Men	Women	Trans
Long-term conditions†	59%	32%	55%	82%	64%	54%	55%	62%	53%	67%
Mental disorders*	37%	39%	38%	36%	46%	23%	37%	39%	33%	53%

†Includes high cholesterol, high blood pressure, diabetes, rheumatoid arthritis, arthritis, osteopenia/ osteoporosis, asthma, chronic obstructive pulmonary disease, erectile dysfunction, kidney disease, sleep disorder/insomnia, neuropathy, dementia, epilepsy, and clinician-validated rarer conditions

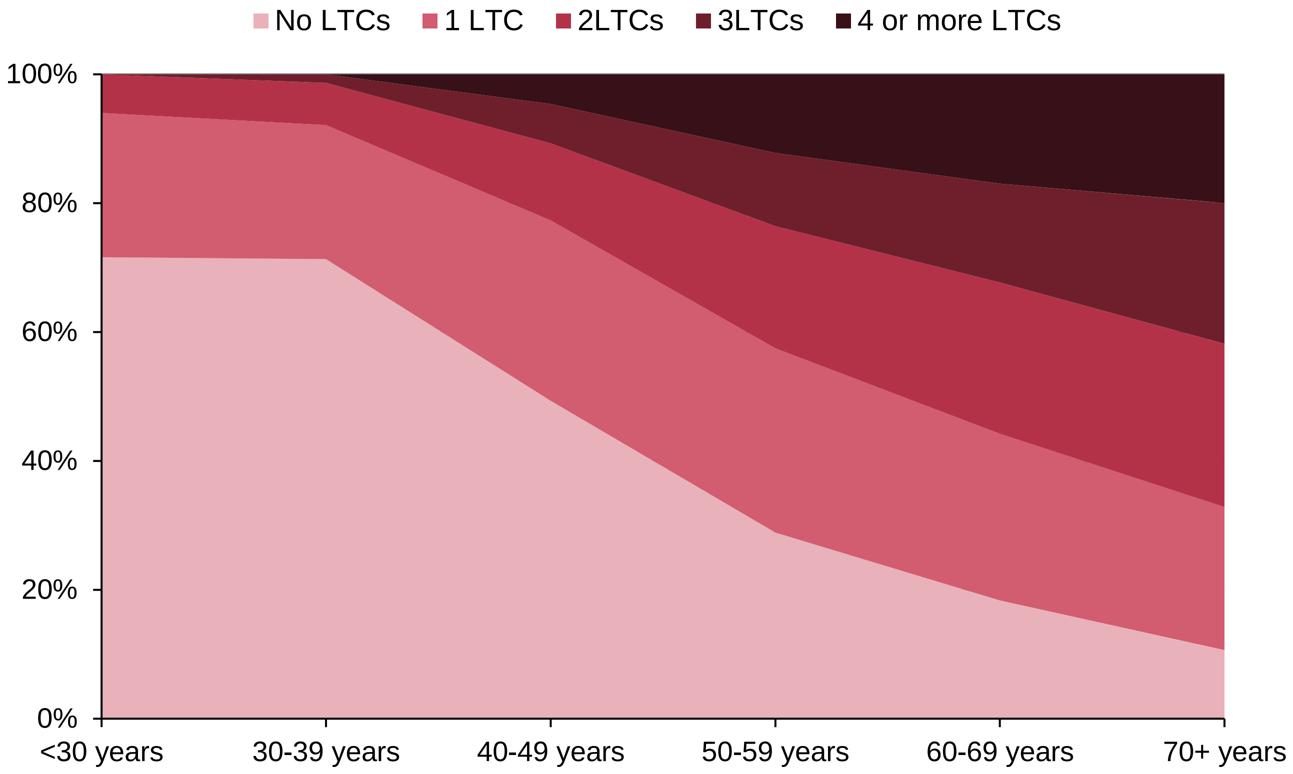
*Mental disorders include anxiety, depression, personality disorder, bipolar disorder, eating disorder, post-traumatic stress disorder, psychosis and schizophrenia and clinician-validated rarer conditions

Multi-morbidity was common, with 1 in 4 (26%) people having one LTC diagnosed in addition to HIV, 15% had 2 LTCs, 9% had 3 LTCs, and 9% had 4 or more LTCs.

[viii] This is likely to be an underestimate the true prevalence as the list in Table 1 is not comprehensive and some participants may have been unable to recall or chose not to voluntarily share other conditions they had previously been diagnosed with. Acute conditions such as heart attack and stroke were excluded, however these may have long-term sequelae. Furthermore, conditions with non-specific symptoms such as chronic fatigue, pain or inflammation were not systematically collected.

Many LTCs are associated with ageing, and therefore the burden among people with HIV also increases with age (Figure 13). By the age of 45, half of people with HIV were living with at least one other diagnosed LTC. By the age of 60, half of people with HIV were living with 2 or more diagnosed LTCs. One in 5 (20%) people with HIV aged 70 or older had 4 or more diagnosed LTCs.

Figure 13: Burden of self-reported diagnosed long-term conditions (LTCs)† in people with HIV by age group



†Includes high cholesterol, high blood pressure, diabetes, rheumatoid arthritis, arthritis, osteopenia/ osteoporosis, asthma, COPD, erectile dysfunction, kidney disease, sleep disorder/insomnia, neuropathy, dementia, epilepsy, and clinician-validated rarer conditions

Polypharmacy

Polypharmacy refers to the concurrent use of multiple prescribed medications. In the case of HIV, where nearly everyone is taking ART, this is defined as taking at least one other clinically prescribed medication in addition to HIV treatment. Polypharmacy was measured in the survey as any self-report prescribed medication for a health condition (including mental health) listed in Table 3[ix]. Current medication was defined as prescribed medication that had been taken in the previous 4 weeks.

[ix] This is likely to be an underestimate of the true level of polypharmacy as the survey did not collect medication for rarer health conditions not listed in Table 1. Short-term medication use was excluded, such as antibiotics or painkillers (unless prescribed for one of the listed conditions). Seasonal medications, such as allergy medication, or intermittent medication, such as for erectile dysfunction or asthma medication, were not included unless taken within the previous 4 weeks. Hormonal medications were not included, such as contraception, hormone-replacement therapy and masculinising/feminising hormones.

Table 3: Prevalence of polypharmacy (HIV treatment plus any other self-reported prescribed medication in the previous 4 weeks) among people living with HIV

	People with HIV (total)	Age Group			Ethnic Group			Gender		
		18-34	35-54	55+	White	Black African	Other minority	Men	Women	Trans
Medication for long-term conditions†	38%	15%	33%	61%	43%	33%	32%	42%	30%	44%
Medication for mental disorders*	20%	12%	18%	27%	26%	11%	16%	21%	15%	25%
Medication for any health condition▲	42%	22%	37%	62%	47%	36%	35%	45%	35%	45%

†Includes high cholesterol, high blood pressure, diabetes, rheumatoid arthritis, arthritis, osteopenia/ osteoporosis, asthma, COPD, erectile dysfunction, kidney disease, sleep disorder/insomnia, neuropathy, dementia, epilepsy, and clinician-validated rarer conditions

*Includes anxiety, depression, personality disorder, bipolar disorder, eating disorder, sleep disorder/insomnia, post-traumatic stress disorder, psychosis and schizophrenia and clinician-validated rarer conditions

▲ Includes all conditions in Table 1 including clinician-validated rarer conditions

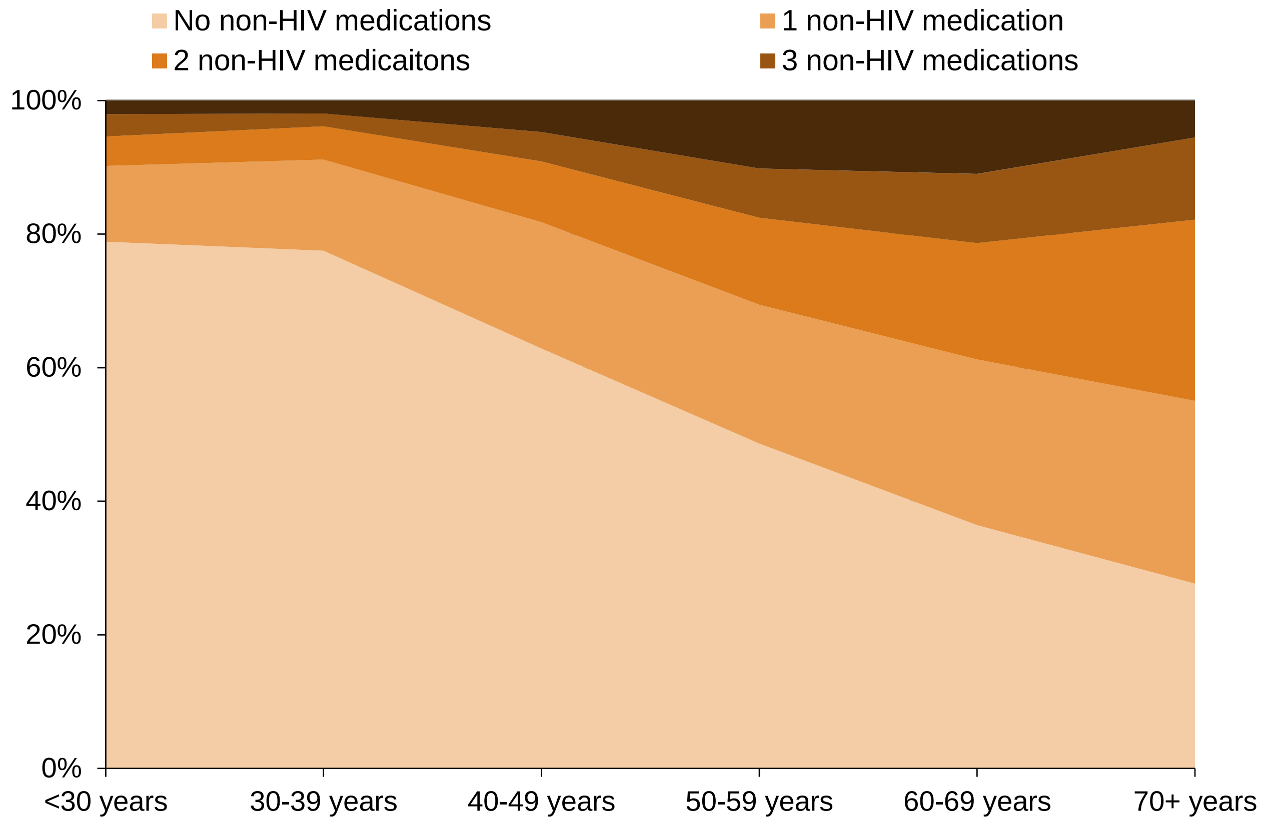
Polypharmacy was common, with 38% of people with HIV currently taking at least one prescribed medication in addition to their HIV medication. The burden of polypharmacy among people with HIV also increased with age, and by the age of 55 years, half of people with HIV were taking HIV treatment and at least 1 other prescribed medication (Figure 14).

People with HIV aged 55 and older were more likely to be taking medication for a mental disorder (27%) compared to younger adults (12% among those aged 18 to 34), despite a similar prevalence of mental disorders in both age groups.

The number of prescribed non-HIV medications taken ranged from 0 to 15. One in 5 (19%) people with HIV were taking one non-HIV medication, 11% were taking 2 non-HIV medications, 5% were taking 3 non-HIV medications, and 8% were taking 4 or more non-HIV medications.

> “I do not think my GP understands the combinations I'm on, or impact of prescriptions on my general wellbeing. I am expected to make all the moves but it’s frustrating to have to keep them to account. Sometimes, it’s not till I do the research that I can then discuss my treatments.” Abdi, 47

Figure 14: Number of non-HIV related prescribed medications taken by people with HIV (in the previous 4 weeks) by age group



> "In my previous clinic a detrimental drug interaction was not picked up for several years. The steroid inhaler and the HIV medicine I was taking were not compatible. I do believe this led to anxiety, depression, and affected my bone density, worsening some joint issues. Whilst I am now managing these conditions and the inhaler has been changed, I do feel this could have been picked up earlier." Henry, 57

Cardiovascular conditions and medications

Cardiovascular conditions included diabetes, high cholesterol, hypertension, heart attack and stroke (including mini-stroke).

Cardiovascular conditions accounted for a significant burden of comorbidity among people with HIV: high cholesterol (29%) and high blood pressure (24%) were the 2 most commonly diagnosed LTCs (excluding mental health conditions) (Figure 15).

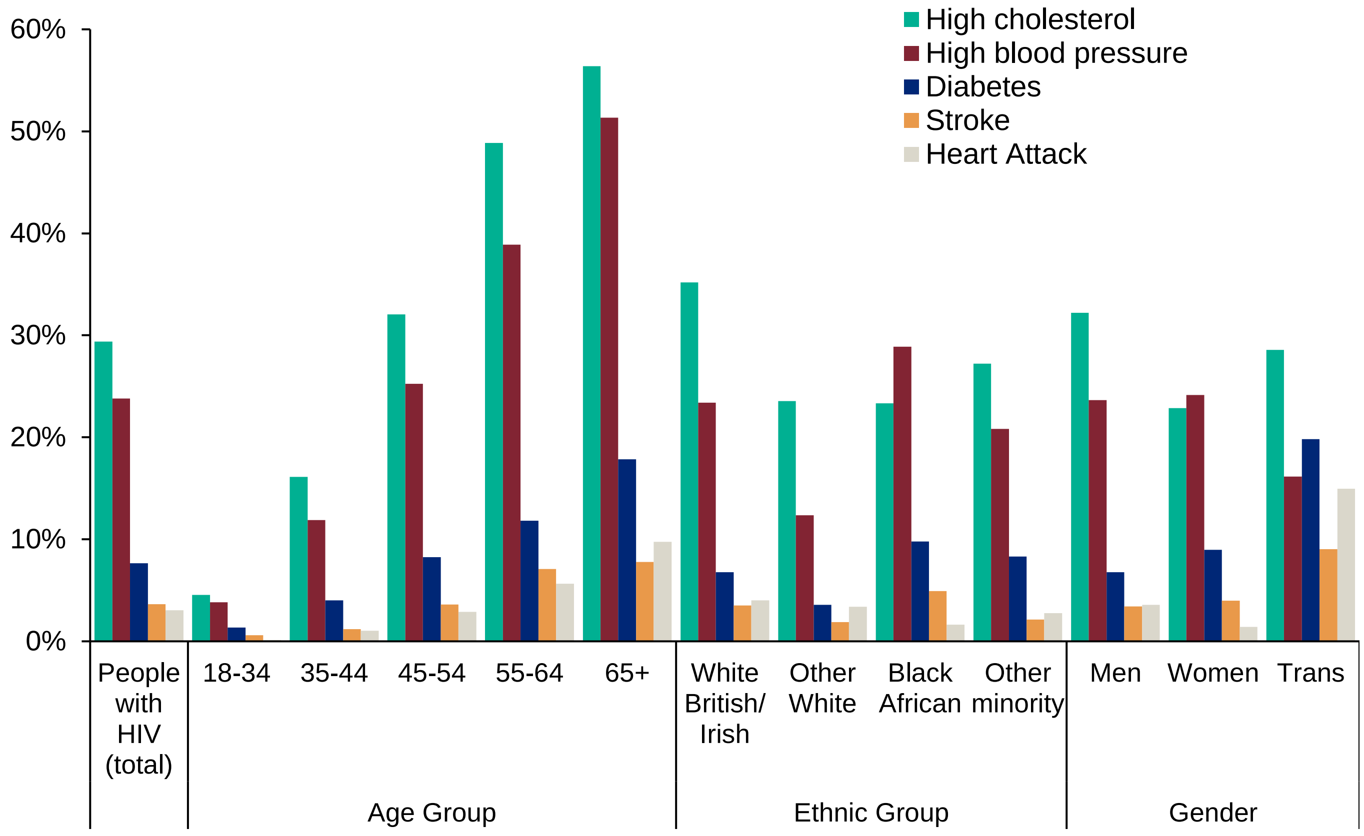
The prevalence of all cardiovascular conditions increased with age. Over half of those aged 65 and older had been diagnosed with high cholesterol (56%) and high blood pressure (51%). One in 10 (10%) people with HIV aged 65 and older had previously had a heart attack.

Cardiovascular disease in people living with HIV varied by ethnicity, following known ethnic variations in disease patterns in the general population. High cholesterol was highest among those of white British/Irish ethnicity (35%), while high blood pressure was highest among black Africans (29%). Likewise, diabetes was highest among black Africans (10%) and other minority ethnicities (8%).

Among men living with HIV, high cholesterol (32%) was most common cardiovascular condition, while among women high blood pressure (24%) was the most common.

Medication was commonly used to treat people's cardiovascular conditions, with 68% of people with high blood pressure taking antihypertensive medication, 54% of people with high cholesterol treating it with medication, and 82% of people with diabetes treating it with medication.

Figure 15: Self-reported prevalence of cardiovascular conditions diagnosed in people with HIV by age, ethnicity and gender



Joint and bone conditions and medications

The joint and bone conditions included arthritis, osteopenia or osteoporosis, and rheumatoid arthritis.

Arthritis was the most commonly diagnosed bone and joint condition in people living with HIV, affecting 11% of people with HIV, followed by osteopenia and osteoporosis (7%) and rheumatoid arthritis (5%) (Figure 16).

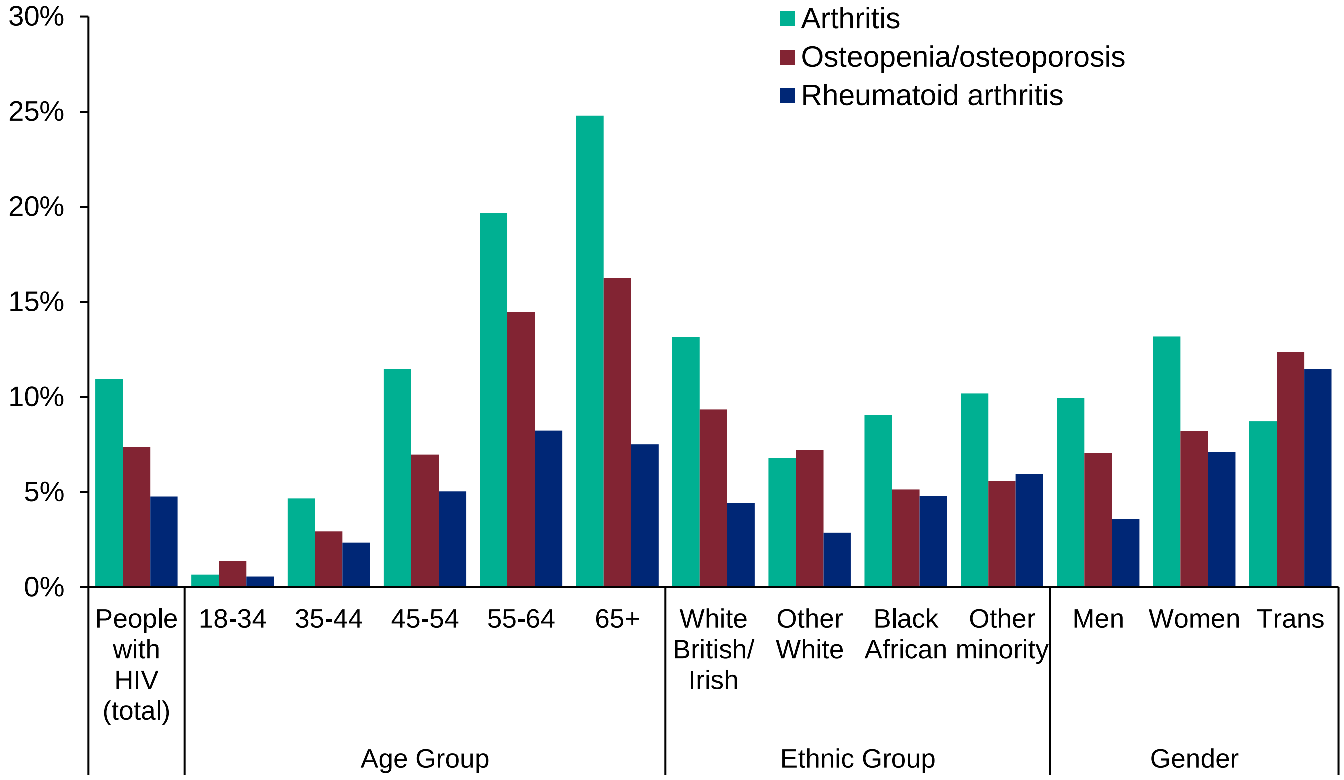
The prevalence of bone and joint conditions increased with age. One in 4 (25%) people with HIV aged 65 and older had been diagnosed with arthritis and 16% with osteoporosis or osteopenia.

As in the general population, bone and joint conditions affected women with HIV more commonly than men, with 13% of women having been diagnosed with arthritis compared to 10% of men, and 7% of women diagnosed with rheumatoid arthritis compared to 4% of men.

Osteoporosis and osteopenia was slightly more common among women (8%) compared to men (7%), and among those of white British/Irish ethnicity (9%) or other white ethnicities (7%) compared to those of black African (5%) or other minority ethnicities (5%). Again, these are similar trends to those seen in the general population.

Medication for bone and joint conditions was less commonly used compared to other conditions, with around half of people taking medication to treat their bone and joint condition.

Figure 16: Self-reported prevalence of joint and bone conditions diagnosed in people with HIV by age, ethnicity and gender



Cancer diagnoses

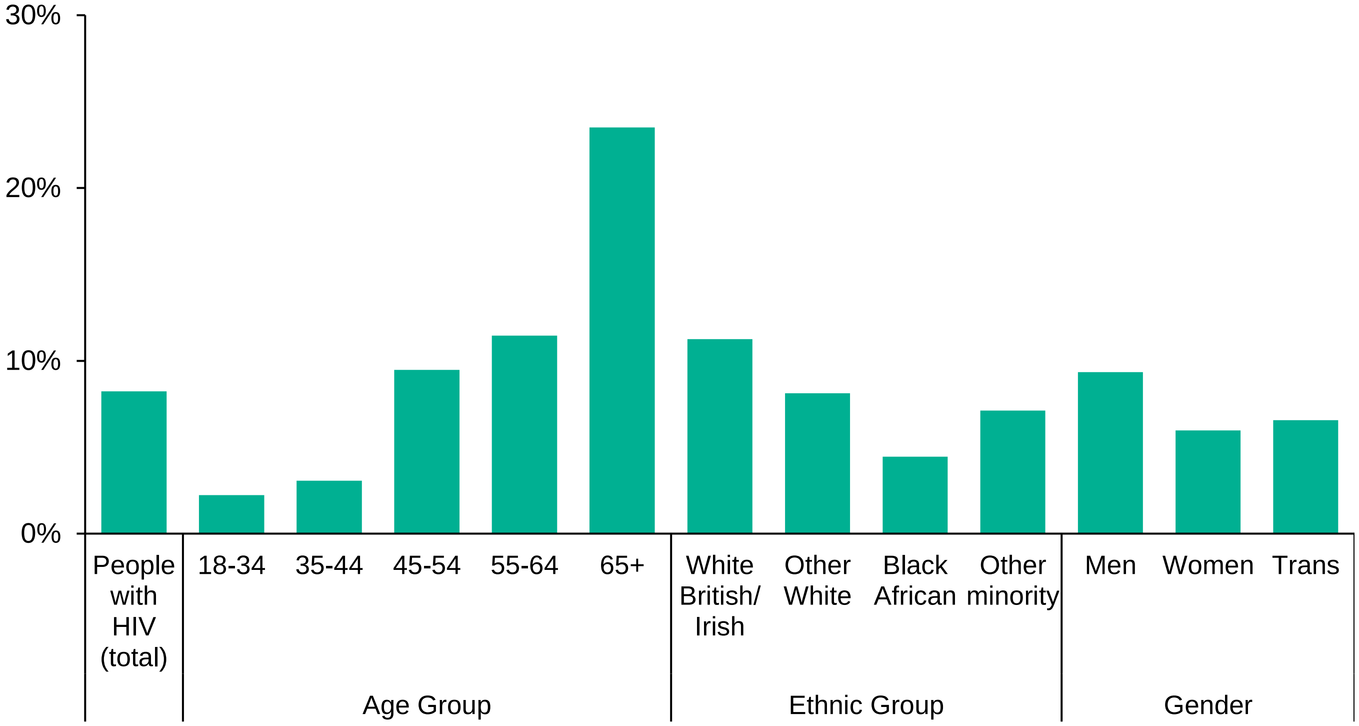
All previous and current cancer diagnoses were reported, with participants specifying the type (basal cell carcinomas, abnormal cells and lesions were excluded).

One in 12 (8%) people with HIV had ever been diagnosed with cancer (Figure 17). The proportion of people who had ever had a cancer diagnosis increased with age, with nearly 1 in 4 (24%) people aged 65 and over having had a cancer diagnosis compared to 2% of those aged 18 to 34. Cancer was also most commonly reported in people of white British/Irish ethnicity (11%) and men (9%).

However, some of the cancers are associated with advanced HIV infection and are known as AIDS-defining conditions. Half (50%) of all reported cancers in people with HIV were AIDS-defining, and half (49%) of these were lymphomas (including non-Hodgkin and Hodgkin lymphoma), 45% were Kaposi's sarcoma (KS), and 5% were cervical cancers.

The other half (50%) of reports cancers were non-AIDS defining (although some could be classed as HIV-related due to higher risk in people with HIV). Over 30 types of non-AIDS defining cancers were reported, and the most common were: skin[x] (25%), prostate (11%), breast (10%), anal (10%), and bowel cancer (8%).

Figure 17: Proportion of people with HIV that report ever being diagnosed with cancer by age, ethnicity and gender



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[x] Skin cancers may be misclassified if they were KS but not specified in the questionnaire

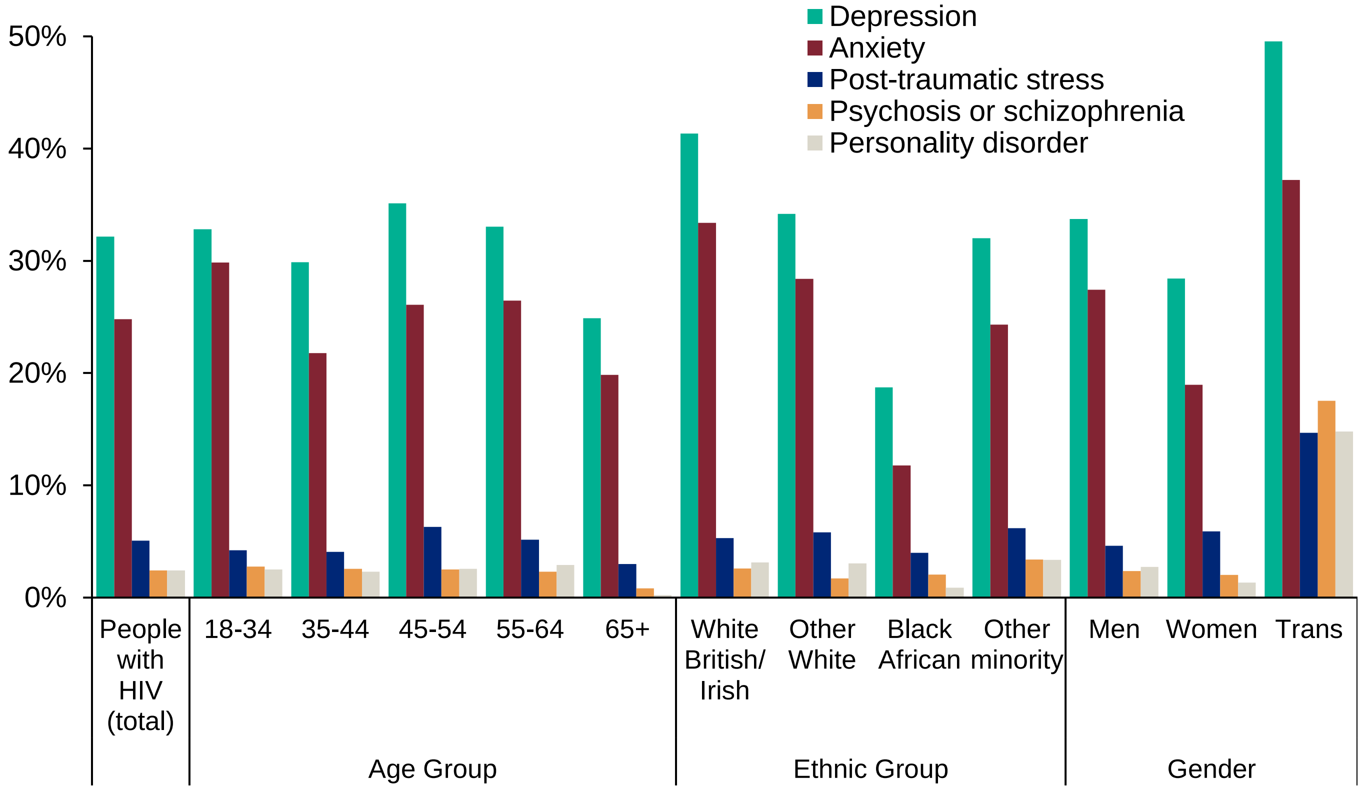
Mental health conditions and medications

Mental health conditions included depression, anxiety, PTSD, personality disorder, eating disorder, bipolar disorder and psychosis/ schizophrenia[xi]. Self-reported ever diagnosed mental health conditions were last collected by Health Survey for England in 2014 and these data were used for comparison to the general population in England.

More than 1 in 3 (37%) people with HIV reported ever being diagnosed with a mental health condition, and the most common conditions were depression (32%) and anxiety (25%) (Figure 18). Prevalence of depression and anxiety was significantly higher in people with HIV compared to the general population in England (depression, 19%; anxiety disorder, 6%)[10]. PTSD was diagnosed in 1 in 20 (5%) people with HIV, in comparison to to 2% of the general population in England.

Serious mental illnesses, such as eating disorders (3%), personality disorders (2%), psychosis/schizophrenia (2%), and bipolar disorder (2%) were rarer in people with HIV, but at least twice as common in people with HIV compared to the general English population (1%, 0.5%, 0.6% and 0.5%, respectively)[10].

Figure 18: Self-reported prevalence of mental health conditions diagnosed in people with HIV by age, ethnicity and gender



[xi] Diagnosed prevalence estimates of mental disorders should be interpreted with some caution as there were more missing data in the year/age at diagnosis compared to physical health conditions, which helps to confirm a diagnosis. This suggests that some reported mental health conditions may be self-diagnosed.

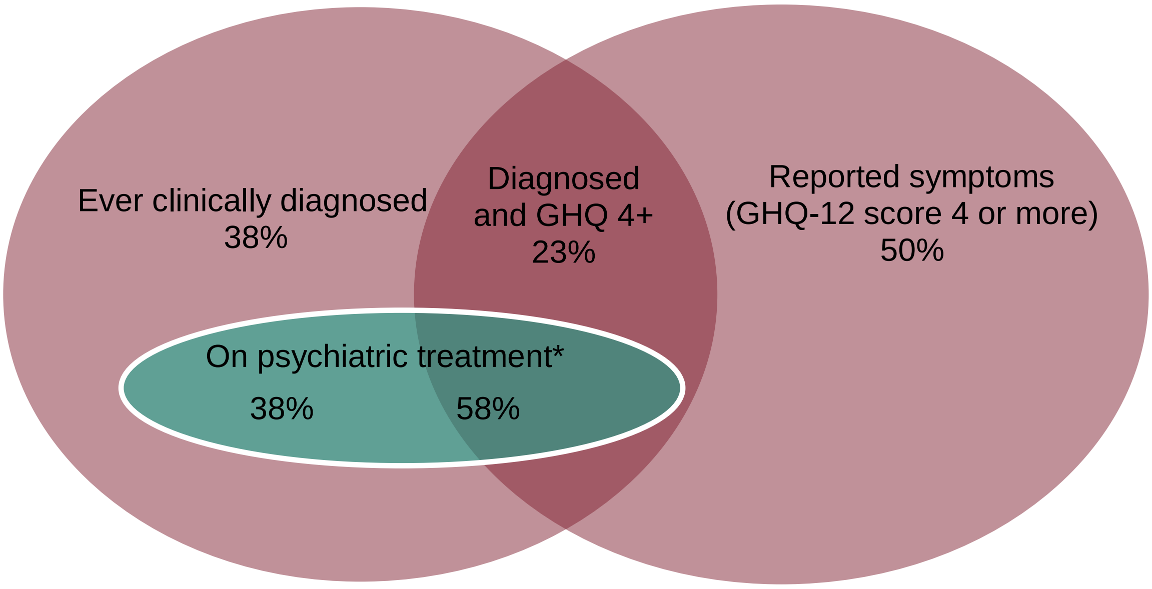
In contrast to the physical health conditions, people of all ages were equally likely to have a mental health diagnosis. Additionally, the average age at diagnosis was younger for mental health conditions (for example, 37 years for depression and 36 years for anxiety) than for physical health conditions (for example, 43 years for high cholesterol and 42 years for arthritis).

In the HIV population, depression and anxiety diagnoses were more common in men and trans people compared to women, and in people of white ethnicity compared to people of black African ethnicity. PTSD and eating disorders were more commonly reported by women than men (6% of women and 5% of men; and 4% of women and 3% of men, respectively).

The use of medication varied by the severity of the mental disorder, with 82% of people with psychosis or schizophrenia and 71% of people with bipolar taking medication for their condition, compared to less than half (46%) and anxiety (48%).

Figure 19 illustrates the overlap between clinically diagnosed mental health conditions and mental health symptoms (as reported by GHQ-12 score 4 or more). This data suggests that 60% of people with HIV who experienced mental ill health were diagnosed, while 40% were undiagnosed. Among those diagnosed, 58% were actively experiencing mental health symptoms were receiving psychiatric treatment, such as medication or professional therapy or counselling.

Figure 19: Venn diagram of the intersection between ever clinically diagnosed mental health conditions, and probable mental ill health (GHQ-12 score 4 or more) with current depression treatment



*Treatment includes current medication for a mental health condition or professional therapy or counselling (in the previous 4 weeks)

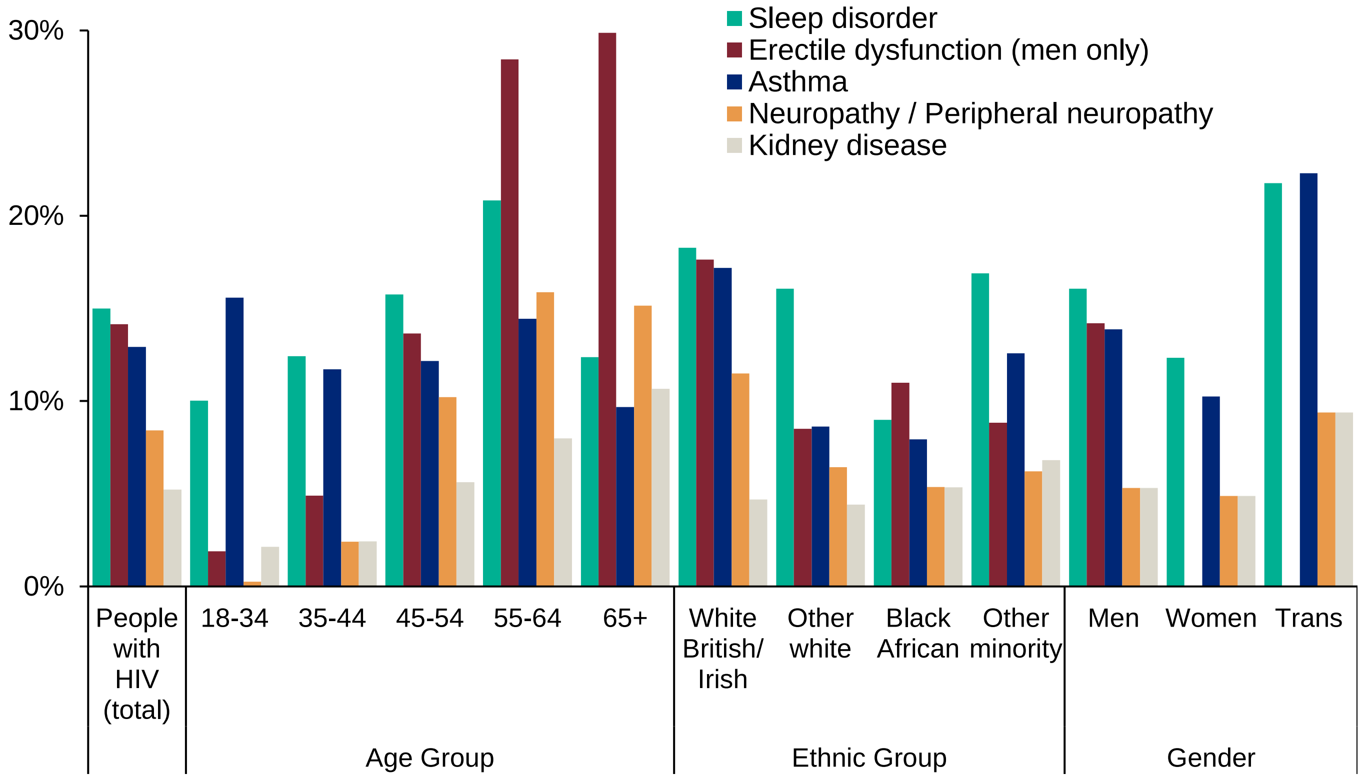
Other long-term health conditions

Other LTCs included asthma, COPD, erectile dysfunction, neuropathy/peripheral neuropathy, kidney (renal) disease, dementia, sleep disorder/insomnia, and epilepsy.

Some of the LTCs were related to HIV infection (Figure 20). Sleep disorder was diagnosed in 15% of people with HIV and was more common in older people, possibly reflecting previous use of neuro-toxic HIV treatment. Neuropathy (including peripheral neuropathy) was diagnosed in 8% of people with HIV and was also more common in older people. Neuropathy is associated with aging but in people with HIV it can also be a long-term consequence of advanced HIV infection. Likewise, in people with HIV kidney disease can be caused by advanced HIV infection or some of the HIV treatments, in addition to factors such as aging, ethnicity, and family history. One in 20 (5%) had been diagnosed with kidney disease; rising to 1 in 9 (11%) people aged 65 and older. Kidney disease was more common in people of black African (5%) and other minority ethnicities (7%), compared to those of white ethnicity.

Asthma was reported by 13% of people with HIV. Unsurprisingly, the prevalence of asthma did not differ by age, but was more prevalent among trans people (22%) and white British/Irish (17%). Over half (58%) of those with asthma had taken asthma medication in the previous 4 weeks. Erectile dysfunction was reported by 14% of men, increasing with age to 29% of men aged 55 to 64 and 30% of men aged 65 and older.

Figure 20: Self-reported prevalence of other long-term conditions diagnosed in people with HIV by age, ethnicity and gender



Viral conditions

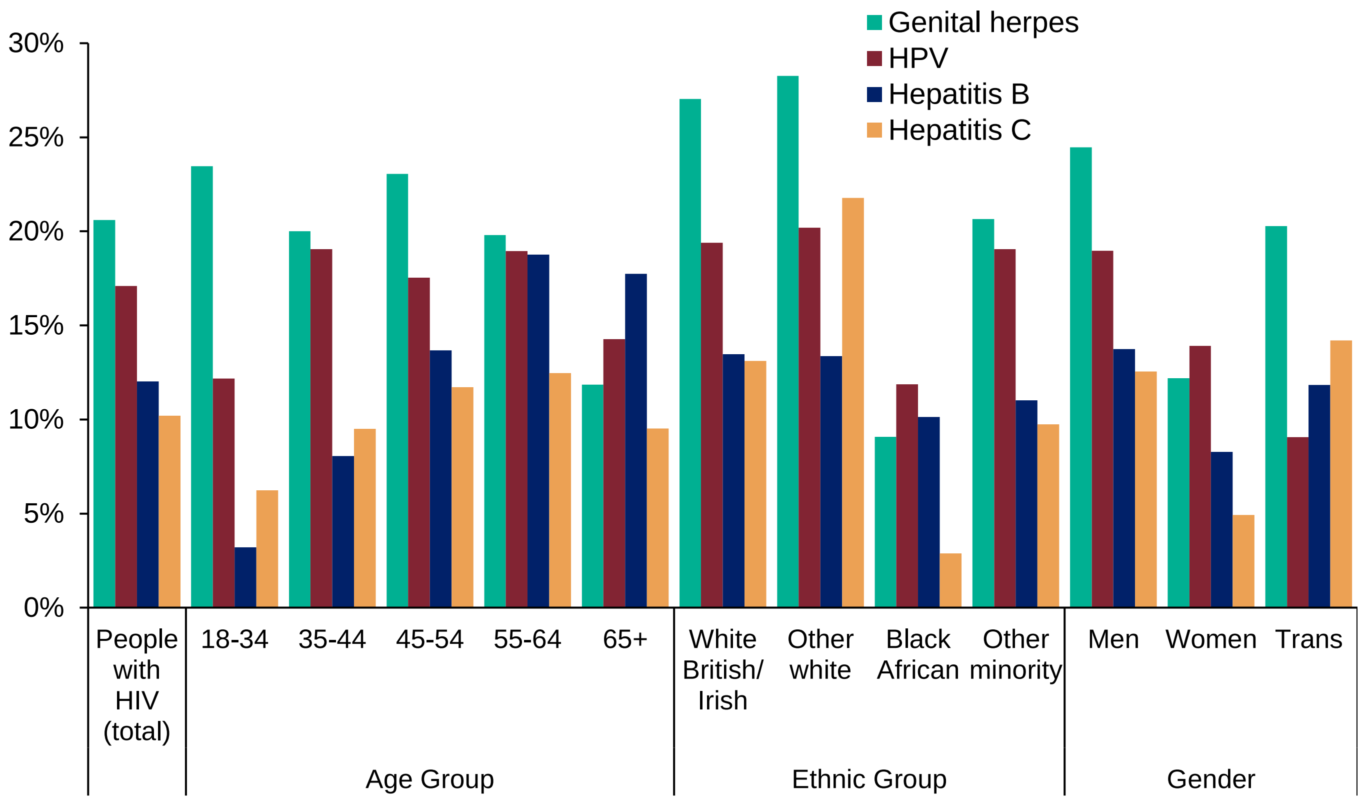
Viral conditions included hepatitis B, hepatitis C, genital herpes, and human papillomavirus (HPV).

The most commonly reported viral condition that had been diagnosed was HPV (21%), followed by genital herpes (17%) (Figure 21). Both conditions were most common among those of white British/Irish ethnicity (27%) or other white ethnicities (28%), men (25%), and people aged 18 to 34 (24%).

Hepatitis B was diagnosed in 12% of people with HIV and was the only viral condition that increased with older age. Only 3% of people aged 18 to 34 diagnosed with hepatitis B compared to 18% of those aged over 50. Hepatitis B was the most common viral condition among women (14%).

Hepatitis C had ever been diagnosed in 10% of people with HIV; prevalence was higher among trans people (14%) and men (13%) compared to women (5%). Hepatitis C was most commonly reported by those of other white (non-British/Irish) ethnicities (22%). Data was not collected on previous hepatitis C treatment and cure, however 1 in 5 (20%) people with hepatitis C were currently taking medication for it.

Figure 21: Self-reported prevalence of viral conditions diagnosed in people with HIV by age, ethnicity and gender



Health service use and satisfaction

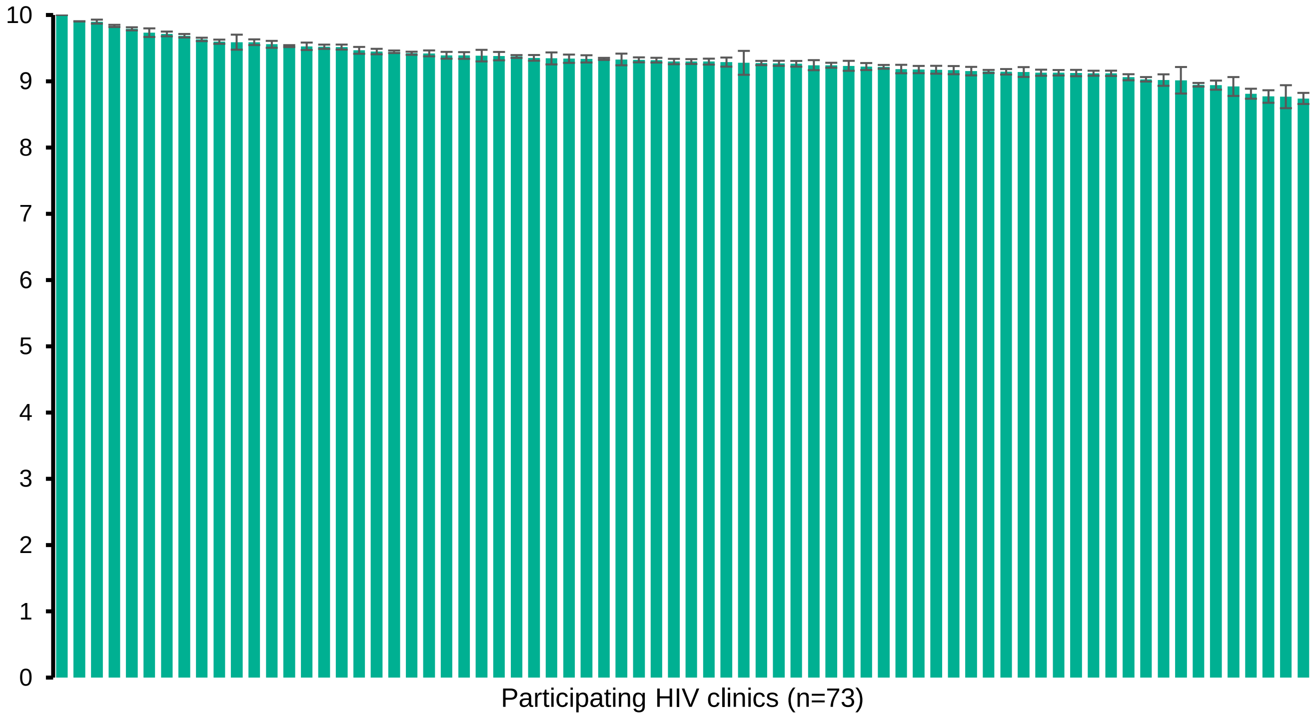
HIV clinical service rating and satisfaction

> “I am happy with the clinic I attend at the moment. The doctors and all nurses are friendly, and they make life easy and bearable for people living with HIV and I am grateful to have them.” Stella, 41

On a scale of 0 to 10, people with HIV were asked to rate their HIV clinical services. Average HIV clinic rating was high, at 9.3 out of 10. There were no differences in HIV clinic rating by age, gender, ethnicity, or socioeconomic status. There was high parity across all 73 participating HIV specialist services, with clinic ratings that ranged from 8.7 to 10 (Figure 22).

People with HIV were asked whether their satisfaction with their HIV clinic had changed compared to 2 years ago. One in 3 (34%) said their satisfaction had increased, 60% said their satisfaction was the same, and 6% said their satisfaction had decreased.

Figure 22: Average clinic rating (on a scale from 0 to 10) in 73 participating HIV clinics



> “I have struggled and suffered with depression in the past but have been fortunate in having fantastic support from my HIV clinic.” Rupert, 56

HIV patient-reported experience measures (PREMs)

Patient experience with HIV specialist services was captured through 5 patient-reported experience measures (PREM) statements about their HIV clinical services:

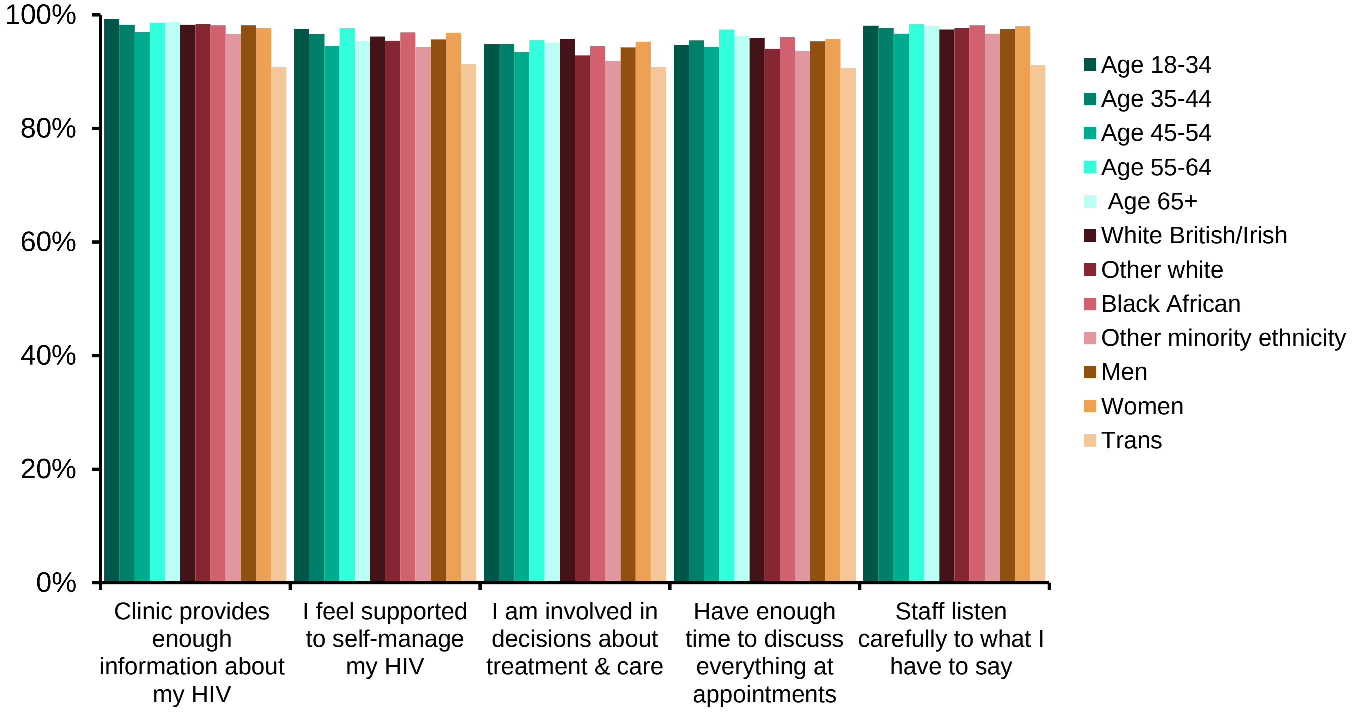
- I have enough information about my HIV
- I feel supported to self-manage my HIV
- I am involved in decisions about my HIV care
- at appointments, I have enough time to cover everything I want to discuss
- the staff listen carefully to what I have to say

People with HIV were asked to agree or disagree (5-item Likert scale with response options “Strongly agree”, “Agree”, “Disagree”, “Strongly disagree” and “Don’t know”). Agreement was defined as “Strongly Agree” or “Agree”.

Agreement to all 5 PREMs was more than 95%, indicating a very positive experience with HIV services overall: 98% said their clinic provided enough information about HIV, 98% said staff listened to what they had to say, 96% felt supported to self-manage their HIV and 95% felt involved in decisions about their HIV care.

Figure 23 shows average agreement to each PREM by demographic. Agreement was 90% or higher for all 5 PREM across all groups, with small non-significant differences observed, indicating that HIV clinical services are highly equitable.

Figure 23: Patient experience with HIV clinical services (% agreement) by age, ethnicity and gender



GP registration and disclosure

> "There's a lack of communication between my GP and HIV clinic. My GP doesn't know my HIV tablet side-effects and my HIV clinic doesn't know my other health problems. I need to be treated as whole, wherever I go for treatment." Nomsa, 60

Nearly all people with HIV (98%) were registered with a GP; of those, 94% had shared their HIV status with their GP. GP disclosure was lowest among young people (aged 18 to 34) (89%), trans people (89%), people of white (non-British/Irish) ethnicity at 90% and other (non-black African) minority ethnicities at 90%.

GP practice rating and satisfaction

People with HIV registered with a GP were asked to rate their GP practice out of 10. On average, people rated their GP practice 6.9 out of 10. GP rating was higher in those in older age groups (GP rating: 6.3 aged 18 to 34 vs 7.8 aged 65 and older). Average GP ratings were lower than ratings of HIV clinical services (6.9 vs 9.3, respectively). However, GP satisfaction closely mirrors that of the general population, with the 2017 British Social Attitudes survey finding GP service satisfaction was 65%[11]. One in 8 (12%) people with HIV indicated that their satisfaction with their GP practice had increased over the previous 2 years, while 61% said their satisfaction was the same, and 14% said their satisfaction had decreased.

GP service patient-reported experience measures (PREMs)

Of people with HIV registered with a GP, experience with GP services was captured with 4 patient-reported experience measure (PREM) statements:

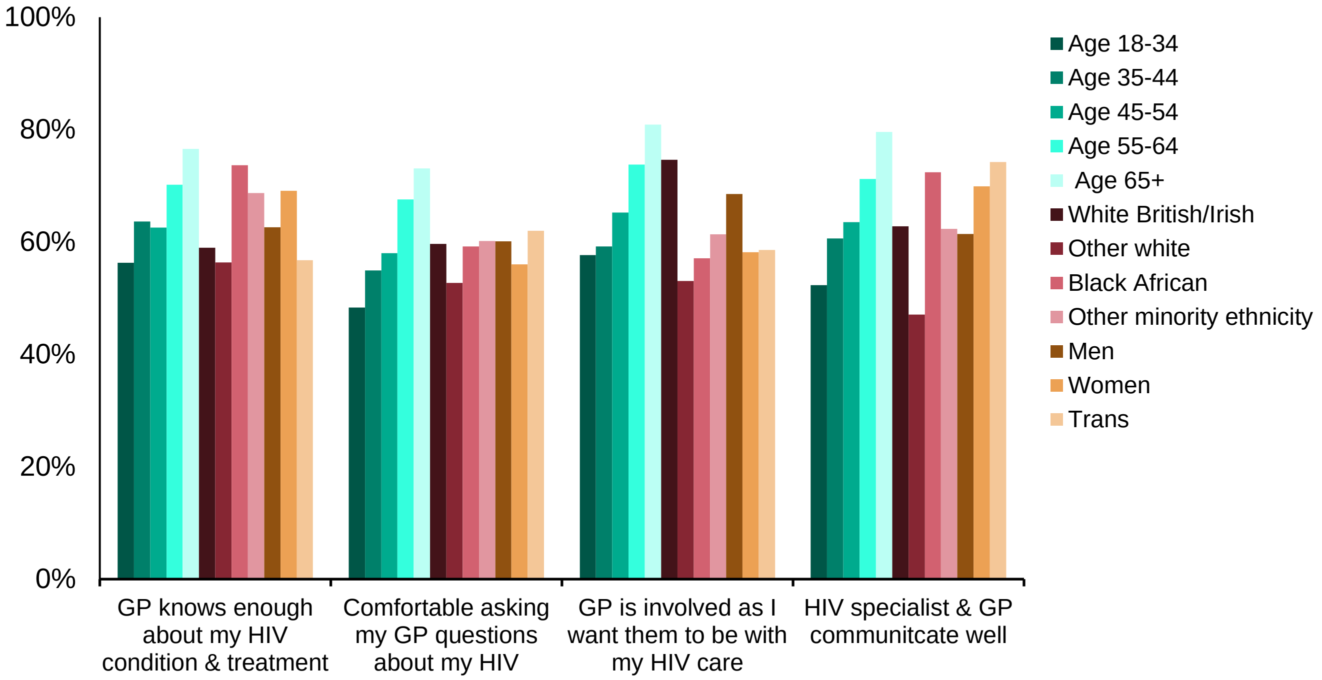
- My GP knows enough about my HIV condition and treatment
- I am comfortable asking my GP questions about my HIV
- My GP is as involved as I want them to be with my HIV care
- I feel that my HIV specialist and my GP communicate well regarding my health

Participants were asked to agree or disagree (5-item Likert scale with response options "Strongly agree", "Agree", "Disagree", "Strongly disagree" and "Don't know").

There was moderate agreement to the GP PREMs: 65% felt their GP was as involved as they want to be in their HIV care, 65% said that their GP knew enough about their HIV condition and treatment, 64% felt that their HIV specialist and GP communicated well and 59% were comfortable asking their GP questions about HIV. One in 5 (20%) of people with HIV did not know whether their HIV doctor and GP communicated well.

Younger people with HIV consistently reported lower satisfaction with GP services (Figure 24). However, there were no other clear differences in GP experience by ethnicity or gender.

Figure 24: Experience with GP services (% agreement) by age, ethnicity and gender



GP attendance

During the previous 3 months, 58% of people with HIV had visited their GP at least once: 43% had been once or twice and 15% had been 3 or more times. Older people were more likely to visit the GP (68% aged 65 and older vs 52% aged 18 to 34).

NHS and social care services

Use of select NHS services in the previous 12 months were collected. The most commonly used services were sexual health clinics (55%) and dentists (52%) (Table 4).

Table 4: Proportion of people with HIV who used that service in the previous 12 months

Service used	Overall	Age 18-24	Age 25-34	Age 35-44	Age 45-54	Age 55+
Sexual health clinic	55%	52%	62%	62%	54%	48%
A&E	20%	12%	21%	20%	21%	19%
Hospital inpatient	11%	1%	10%	10%	11%	12%
Dentist	52%	27%	40%	49%	54%	60%
Occupational therapy	5%	2%	4%	5%	5%	6%

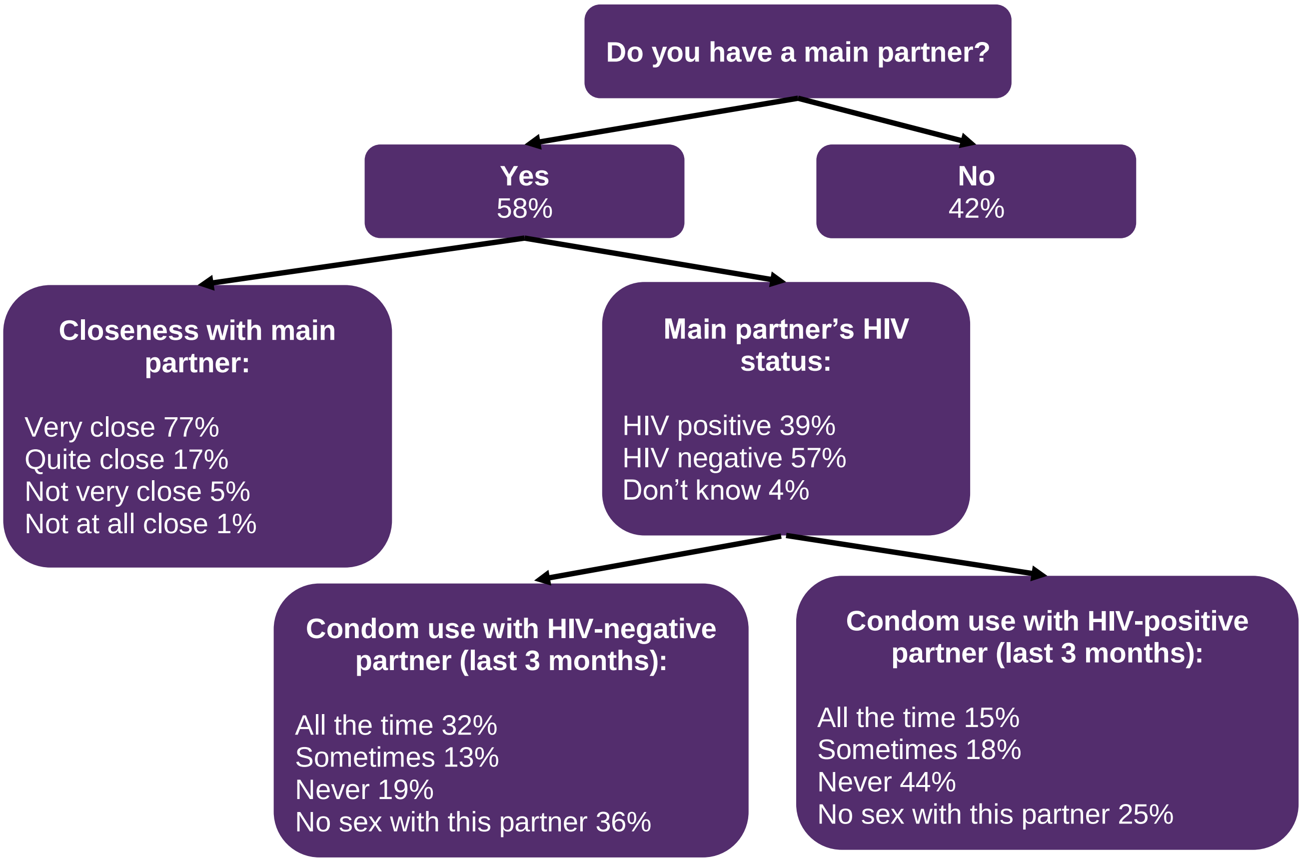
Sex and Relationships

Relationships with main partner

Over half (58%) of people with HIV had a main partner[xii]: 57% reported that their partner was HIV-negative, 39% said that their partner was HIV-positive, and 4% did not know their partner's HIV status (Figure 25). Of those people with a main partner, the majority (94%) said they felt close to them. Women with HIV were twice as likely to say they did not feel close to their partner (10%) when compared to men (5%).

The sexual behaviour of people with HIV varied depending on whether their partner was HIV-negative or HIV-positive. People who had HIV-negative partners were more likely to use condoms all the time (32% vs 15% of those with HIV-positive partners) or to be sexually abstinent (36% vs 25% of those with HIV-positive partners). Considering over 95% of people were virally suppressed, these data suggest that not all people with HIV know or believe that being on HIV treatment with an undetectable viral load means they cannot pass on HIV sexually (undetectable equals untransmittable (U=U)).

Figure 25: Current relationship status, partner's HIV status and condom use



[xii] In the survey, main partner is defined as "the person you feel committed to above anyone else. This is a person you would call your partner, spouse, girlfriend/boyfriend, or husband/wife."

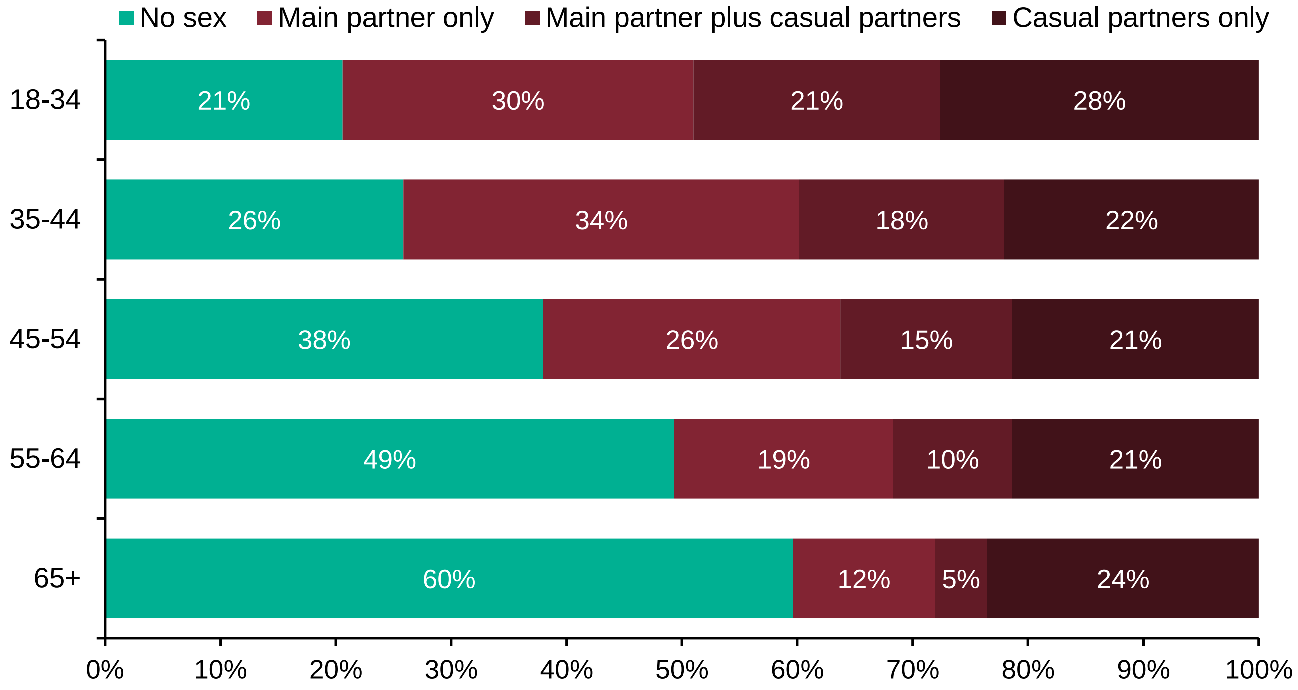
Sexual partners

People with HIV were asked about the sexual partnerships they have had over the previous 3 months, including sex with main partners and casual partners[xiii].

Over 1 in 3 (36%) people with HIV had not had sex in the previous 3 months. Of those who were sexually abstinent, 36% reported being in a relationship with a main partner (with whom they had not had sex). Just under two-thirds (64%) had had no partners during this time; this equated to 24% of people with HIV who were neither in a relationship nor had sex in the previous 3 months. Rates of sexual abstinence in people with HIV increased with older age (Figure 26).

In the previous 3 months, 1 in 4 (26%) people with had had sex with a main partner only, 23% had had sex with casual partners only, and 15% had sex with both a main partner and casual partner(s). The proportion of people with HIV who were sexually active (in the previous 3 months) was similar for gay and bisexual men (69%) and heterosexual men (65%), but slightly lower for women (58%).

Figure 26: Sexual partners in the previous 3 months by age



The total number of gay and bisexual and other men who had sex with men was calculated, considering both self-identified sexual orientation (gay or bisexual men) and sexual behaviour (any male main partners or casual partners). Overall, 98% of gay and bisexual men identified as gay or bisexual (92% as gay and 7% as bisexual). Only 0.7% (or 13 men) gay and bisexual men identified as heterosexual, 0.7% as “other” sexual

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[xiii] In the survey, casual partner is defined as “sexual partners you have had in the previous 3 months, apart from a main partner, if you have one”

orientation, and 0.4% said “Prefer not to say”. Over half (53%) of gay and bisexual men reported having sex with one or more casual male partners in the previous 3 months. The median number of partners was 3 and the average was 7 partners; this average was skewed due to the wide range of partners from 1 to 350.

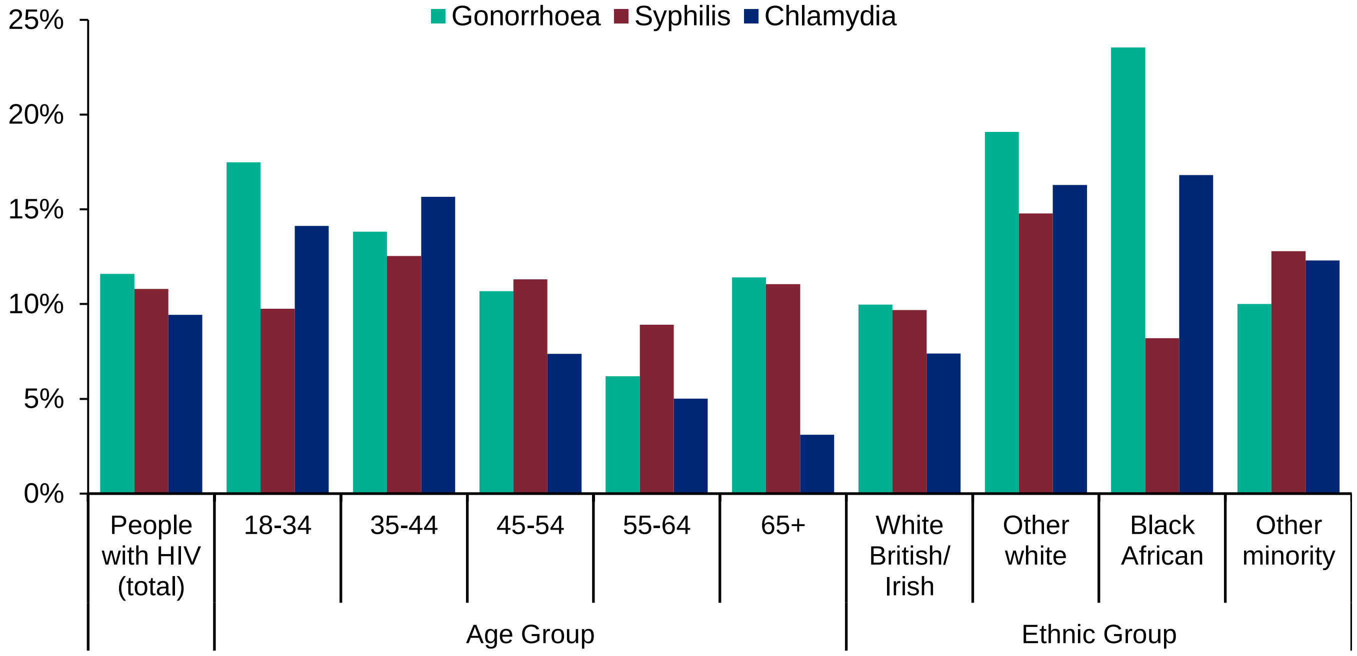
Heterosexual men and women reported fewer partners than gay and bisexual men. Among heterosexual women[xiv], 26% reported one or more casual male partners: 94% reported 1 male partner and 6% reported 2 male casual partners. Among heterosexual men[xv], 23% reported one or more casual female partners: 78% reported 1 male partner and 14% reported 2 male casual partners.

Sexually transmitted infections

People with HIV were asked to report any bacterial sexually transmitted infections (STIs) [xvi] diagnosed in the previous 3 months. Overall, 1 in 9 (11%) people with HIV had been diagnosed with a bacterial STI; the proportion in gay and bisexual men was higher than in heterosexual men and women (19%, 5% and 4%, respectively). The most common STIs were syphilis (6%), gonorrhoea (6%) and chlamydia (6%).

Figure 27 shows the proportion of gay and bisexual men with HIV diagnosed with an STI in the previous 3 months by age and ethnic group. The overall picture suggests that younger and non-white British/Irish gay and bisexual men had higher rates of STIs.

Figure 27: Proportion of gay and bisexual men with HIV diagnosed with an STI in the previous 3 months, by age and ethnic group



[xiv] Women who identified as heterosexual and/or reported sexual activity with men only
[xv] Men who identified as heterosexual and/or reported sexual activity with women only
[xvi] Chlamydia, gonorrhoea, syphilis, lymphogranuloma venereum (LGV), or shigella

Women’s sexual and reproductive health

In total, 1,162 cisgender women with HIV completed the section on women’s sexual and reproductive health. Their average age was 46 years (ranging from 18 to 84 years). Of these women, 66% were of reproductive age (defined as between 15 and 49 years).

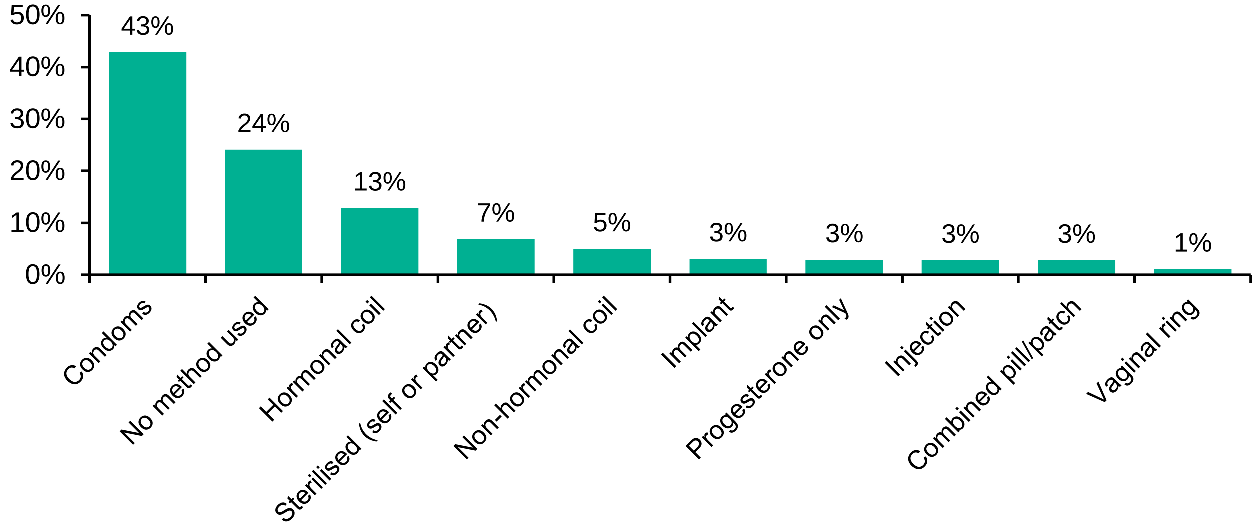
Pregnancy

At the time of completing the survey, 1 in 20 (5%) women were currently pregnant or had been pregnant within the previous year (aged 22 to 47 years). Among women of reproductive age, 3% were actively trying to conceive (aged 23 to 46 years).

Contraception use

Among sexually active women of reproductive age[xvii], 24% women with HIV used no form of contraception (Figure 28). The most common form of contraception used was condoms (43%). One in 4 (26%) used hormonal contraceptives, and 5% used both hormonal contraceptives and condoms.

Figure 28: Contraceptive use among sexually active women with HIV (aged 18-49 years)



Menopause

Menopausal stage of women with HIV was derived using their age, time since last menstrual period, frequency of missed periods, recent pregnancies and contraception use. Overall, 61% (mean age of 40 years) of women were in the reproductive or pre-menopausal stage, 3% (mean age of 48 years) were in the menopause transition or peri-menopausal stage and 36% (mean age of 55 years) were post-menopausal.

[xvii] Women aged 18 to 49 years who reported sex with any partner in the previous 3 months

Lifestyle risk behaviours

Height, weight and BMI

Body mass index (BMI) is a health metric that is used to assess whether a person is a healthy weight and to predict risk for chronic conditions like cardiovascular and metabolic diseases[xviii]. BMI is calculated by dividing weight in kilograms by height in metres squared and categorised using the World Health Organisation's classifications[13]:

- **Underweight:** Less than 18.5 kg/m^2
- **Healthy weight:** 18.5 kg/m^2 to less than 25 kg/m^2
- **Overweight**: 25 kg/m^2 to less than 30 kg/m^2
- **Obese:** 30 kg/m^2 or more

Overall, 41% of people with HIV were a healthy weight and only 2% were underweight. However, over half (57%) were overweight (33%) or obese (24%).

Figure 29: Proportion of people with HIV classified as overweight or obese (BMI 25 kg/m^2 or more), compared to the general English population

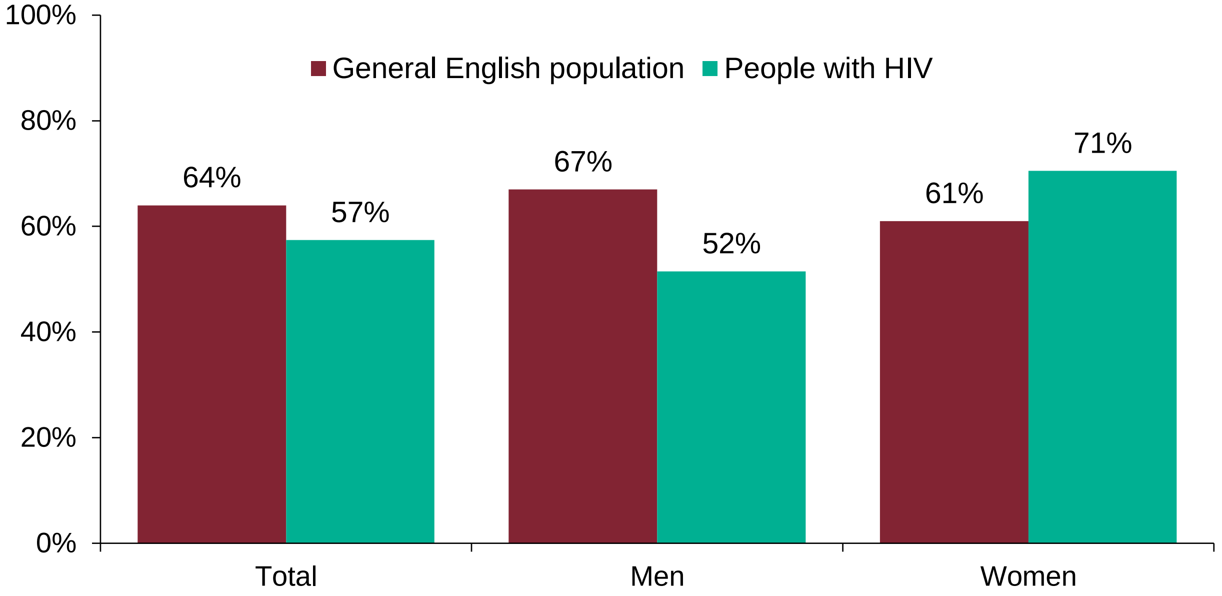


Figure 29 shows the prevalence of overweight and obesity (BMI≥25 kg/m2) in people with HIV compared to the general population in England[14]. This reveals a striking contrast by gender, where women with HIV are more likely to be overweight or obese

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[xviii] An increasing body of evidence shows that BMI is not necessarily a good indicator of a person's overall health, as it does not account for different ratios of muscle to fat mass. Research has shown that BMI may overestimate fatness in people of black, Asian or other minority ethnic populations. However, there is strong evidence that people of non-white backgrounds have increased risk for health conditions like type 2 diabetes at a lower BMI than their white counterparts. Clinicians should follow NICE guidelines for interpreting BMI scores in the context of ethnic background [12].

(71% vs 61% among women in the general population in England) and men with HIV are less likely (52% vs 67% among men in the general population in England). Overweight and obesity was highest among people of black African ethnicity; 80% of black African women and 71% of black African men.

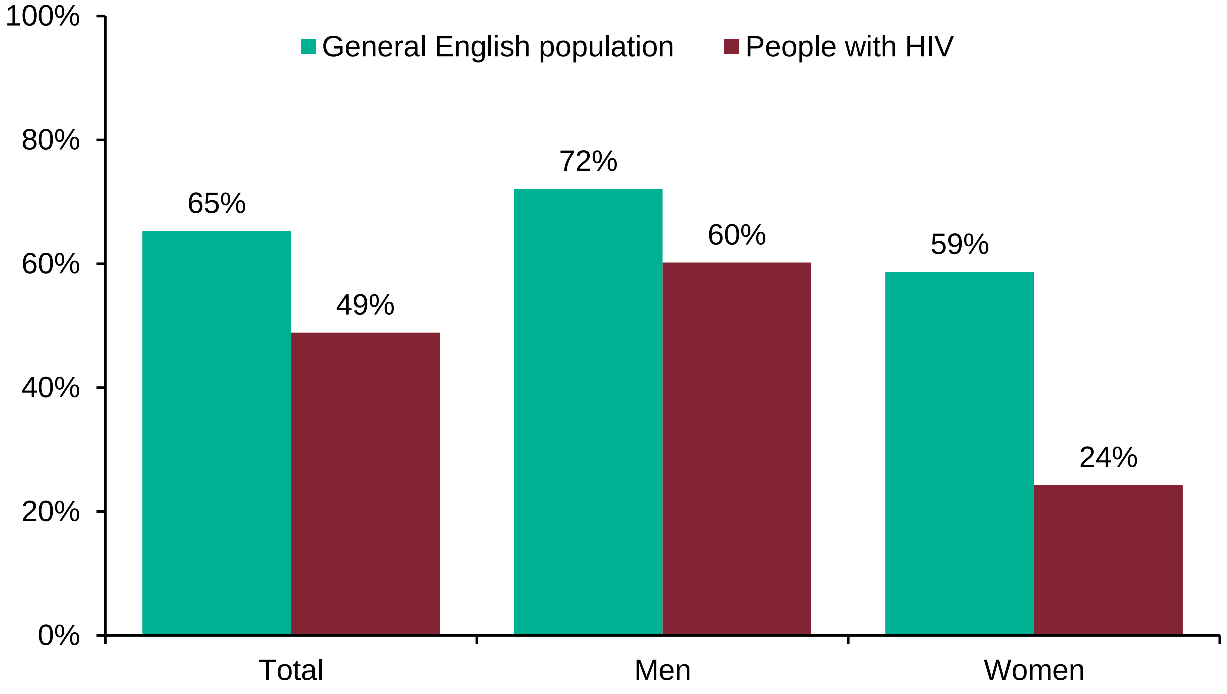
Alcohol and tobacco use

> "I thought I could handle everything on my own but the reality of being positive takes a while to sink in and the impact it has on your social and sex life wears you down…. It was then that I developed issues with drugs and alcohol." Sajid, 32

The survey asked people with HIV about their alcohol use using the AUDIT-C scale. Binge drinking was defined as consuming 8 or more units of alcohol for men or 6 or more units of alcohol for women on a single occasion. Regular drinking was defined as having on average one or more drinks of alcohol per week.

One in 4 (27%) people with HIV were non-drinkers and a further 1 in 4 (24%) drank only occasionally (monthly or less). People with HIV were less likely to be regular drinkers than the general population in England (49% versus 65%, respectively) (Figure 30)[14]. This disparity was driven by lower rates of alcohol use among women (24%) and black Africans (27%). Regular drinking was more common among white British/Irish (64%) and gay and bisexual men (65%).

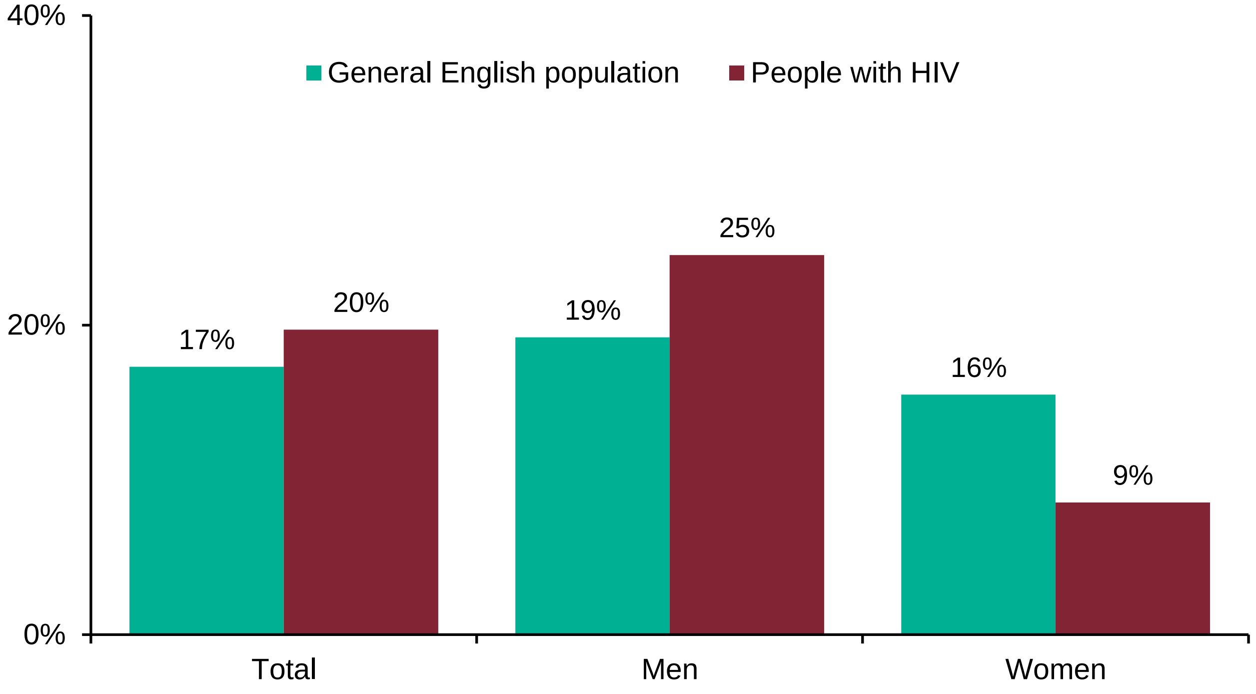
Figure 30: Proportion of people with HIV reporting regular alcohol use (at least weekly), compared to the general English population



Binge drinking (in the previous week) was reported by 15% of people with HIV; the same as in the general English population[14]. Men with HIV also reported the same rates of binge drinking (19%) as men in the general population (19%). The prevalence of binge drinking was highest for gay and bisexual men (20%). Women with HIV reported lower rates of binge drinking (6%) compared to women in the general population in England (11%).

One in 5 (20%) of people with HIV were current smokers, compared to 17% of the general population in England (Figure 31)[14]. Over half (52%) had never smoked and 28% were previous smokers. Smoking was most common among young people aged 18 to 34 (30%) and gay and bisexual men (26%).

Figure 31: Proportion of people with HIV who are current smokers compared to the general English population



Recreational drug use

> “I have been waiting 6 months for mental health services. Methamphetamine is helping me control my day to day well-being and has been filling the void in the delay in accessing proper mental health services. My GP sees me as an addict and won’t prescribe treatment. Tomorrow I see a psychiatrist.” Lee, 42

People with HIV indicated which drug(s) they had used in the previous 3 months from a comprehensive list of 12 drugs (listed alongside their street names).

Overall, just under 1 in 4 (23%) people with HIV reported taking recreational drugs in the previous 3 months, and 77% had not taken drugs. Drug use was highest among gay and bisexual men (40%), young people aged 18-34 (38%) and trans people (35%).

The most common drugs used by people with HIV were cannabis, nitrates (poppers) and cocaine (12%, 8%, and 7%, respectively) (Table 5). Younger people with HIV aged 18 to 34 were most likely to use cocaine (17%) and ecstasy (9%), while gay and bisexual men were most likely to use nitrates (poppers) (16%). Around 1 in 20 gay and bisexual men and young people (aged 18 to 34) had used ketamine in the previous 3 months.

Recreational drug use was lower in other groups; 17% of heterosexual men and 5% of women. Use of heroin and crack were rarely reported, at 0.5% and 0.8%, respectively.

Table 5: Recreational use among people with HIV in the previous 3 months

	Overall	Age		Gender			Risk group	
		18-34	35+	Men	Women	Trans	Gay and bisexual men*	Black African
Cannabis	12%	22%	11%	15%	4%	20%	18%	3%
Nitrates	8%	11%	8%	11%	<1%	14%	16%	<1%
Cocaine	7%	18%	6%	10%	1%	18%	13%	<1%
Methamphetamine	5%	9%	5%	7%	<1%	4%	10%	<1%
GHB/GBL	5%	14%	4%	7%	<1%	7%	9%	<1%
Mephedrone	4%	9%	4%	6%	<1%	7%	9%	<1%
Ecstasy	4%	9%	3%	5%	<1%	8%	7%	<1%
Ketamine	2%	5%	2%	3%	<1%	6%	4%	<1%
Amphetamine	1%	4%	<1%	1%	<1%	2%	2%	<1%
Crack	<1%	2%	<1%	<1%	<1%	8%	<1%	<1%
Heroin	<1%	1%	<1%	<1%	<1%	3%	<1%	<1%
Acid	<1%	<1%	<1%	<1%	<1%	<1%	<1%	<1%

* Defined as men whose self-identified sexual orientation is gay or bisexual and/or reported sex with any male partners

Chemsex and slamming

This section describes chemsex and slamming among gay and bisexual men with HIV[xix]. Chemsex refers to the use of drugs before or during sex to increase pleasure and stamina and to reduce inhibitions. Chemsex was defined as using mephedrone, methamphetamine and/or GHB/GBL before or during sex. Slamming is defined as injecting drugs or being injected with drugs (slammed) before or during sex. Slamming was defined as injecting crystal meth and/or mephedrone before or during sex.

[xix] Defined as men whose self-identified sexual orientation is gay or bisexual and/or reported sex with any male partners

Among sexually active gay and bisexual men[xx], 20% reported chemsex in the previous 3 months. All 3 of the chemsex drugs were used with similar frequency: crystal meth (13%), GHB/GBL (12%) and mephedrone (11%). Cocaine was used by 11% of gay and bisexual men before or during sex, 6% used ecstasy and 4% used ketamine before or during sex. Chemsex was most common among gay and bisexual men aged 35 to 44 (28%) and men of non-British/Irish white ethnicity (25%).

Among sexually active gay and bisexual men, 7% reported slamming in the previous 3 months, which represented more than a third (34%) of those who reported chemsex. Slamming prevalence was similar across all age and ethnic groups.

Injection drug use

One in 10 (10%) people with HIV reported ever having injected non-prescribed drugs, of which, 28% were current injectors (injected in the previous month), 17% recent injectors (injected in the previous year), and 55% previous injectors (last injected more than a year ago).

People with HIV of non-British/Irish white ethnicity reported the highest lifetime prevalence of injecting drugs (24%). Men with HIV were more likely to report ever injecting drugs (13%) compared to women (2%). However, slightly less than 1 in 5 (19%) trans people reported ever injecting. Younger people aged 18 to 34 were more likely to report ever injecting drugs (15%) compared to 2% of people aged 65 and older.

Among people with HIV who had ever injected drugs, 42% had been diagnosed with hepatitis C and 22% had been diagnosed with hepatitis B.

[xx] Gay and bisexual men who reported sex with any partner in the previous 3 months (68.6% of gay and bisexual)

Stigma and discrimination

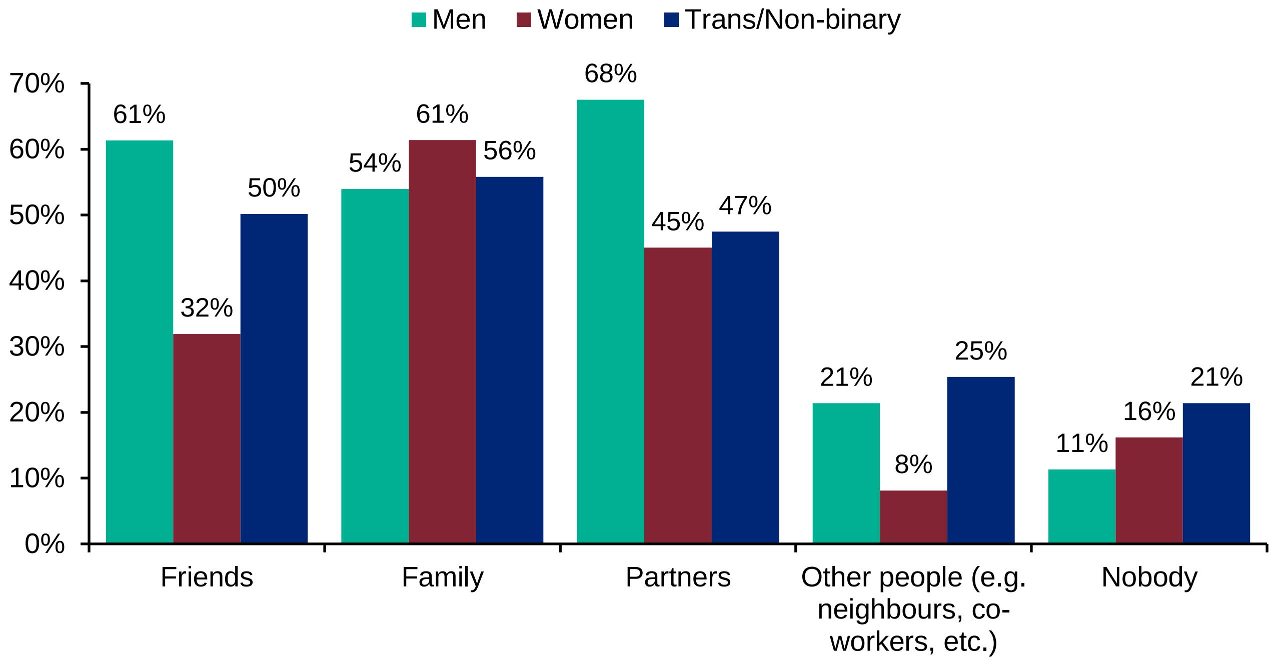
> "[I am] still very conscious and almost ashamed of the fact that I am HIV positive. While society has come a long way, there is what I perceive to be a lot of judgement towards people living with this disease. A lonely illness to have." Gloria, 66

Disclosing HIV status outside healthcare settings

One in 8 (13%) people had not shared their HIV status with anyone outside of a healthcare setting (Figure 32). Non-disclosure was most common in trans people, with 1 in 5 (20%) not disclosing their HIV status to anyone. Non-disclosure was more common among heterosexual men (19%) and women (16%) compared to gay and bisexual men (8%). Non-disclosure was also more common among people of black African (17%) and other minority ethnicities (17%) compared to people of white British/Irish ethnicity (9%) or other non-British/Irish white ethnicity (11%).

Of the 87% of people shared their HIV status, 60% told their sexual partners, 56% told family members, 52% told friends, and 17% told others, such as co-workers and neighbours. Women with HIV were most likely to tell family but least likely to tell their friends and partners. However, men were the opposite: they were most likely to tell their friends and partners and least likely to tell family.

Figure 32: Proportion of people that disclosed their HIV status and who they told



> "I don't feel comfortable telling anyone about my HIV. [It is] very difficult in general but far worse in the Asian culture. I am ashamed to even tell my family." Hamza, 43

HIV-related stigma and discrimination in healthcare settings

> “I believe GP staff need more HIV education… so that people like me are not put in a position where you would rather die of pain than go to the GP when there’s a need.” Lethabo, 39

Internalised stigma and fear of discrimination were commonly reported by people with HIV. In the previous 12 months, 1 in 6 (16%) people with HIV worried about being treated differently to other patients due to their HIV status, while 1 in 10 (10%) avoided seeking healthcare when they needed it because of their HIV.

Perceived and experienced discrimination were less common. One in 13 (8%) felt they had been treated differently to other patients. One in 20 (5%) felt they had been refused healthcare or delayed a treatment or procedure because of their HIV status.

Women with HIV were most likely to report internalised stigma, with 1 in 5 (21%) worried about being treated differently because of their HIV (Figure 33). Londoners with HIV report less stigma or discrimination in healthcare settings, with people with HIV in the North of England reporting the highest rates of stigma and discrimination for all 4 stigma questions in the survey (Figure 34).

Figure 33: HIV-related stigma and discrimination in healthcare settings by gender (in the previous 12 months)

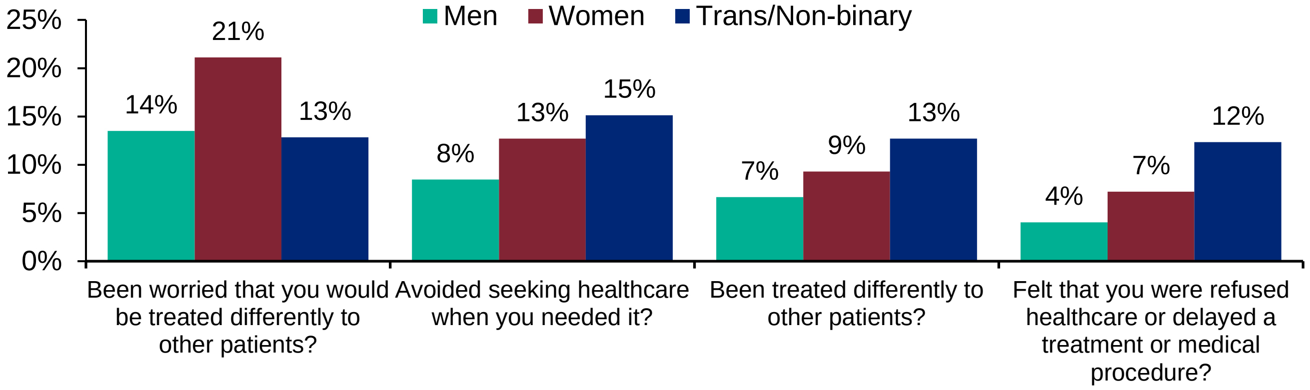
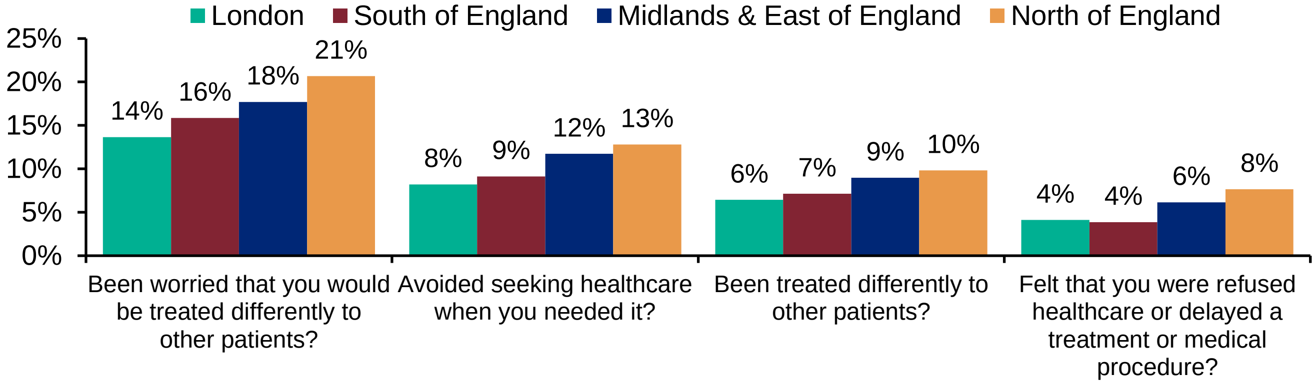


Figure 34: HIV-related stigma and discrimination in healthcare settings by geography of residence (in the previous 12 months)



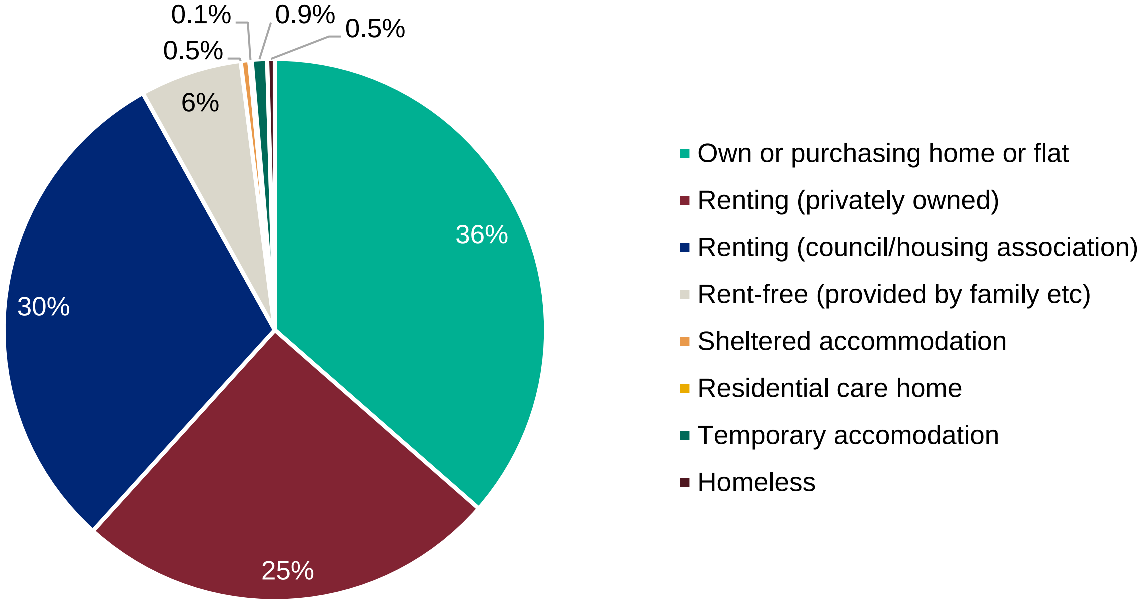
Housing, work and finances

Housing

Just over one in 3 (37%) people with HIV were home owners (of a house or flat) while 25% reported renting a privately-owned home and 30% were renting from a council or housing association (Figure 35).

Six percent were living rent-free in accommodation provided by their friends or family. The remainder were living either in some form of temporary accommodation (0.9%), were homeless (0.5%), living in sheltered accommodation (0.5%), or a residential care home (0.1%) at the time they completed the questionnaire.

Figure 35: Housing and accommodation of people living with HIV



Employment status

Current employment status was aligned to the Office of National Statistics (ONS) estimates of employment and economic activity to define employment status and calculate unemployment rates[15]:

Employed: those who actively contribute to the economy include those employed to some extent, whether full-time, part-time or self-employed.
Economically inactive: those currently not working or contributing to the economy but are not considered unemployed because they are unable to seek employment. This includes being an asylum seeker, stay at home parent or carer, full-time student, retired, or long-term or temporarily sick or disabled person.

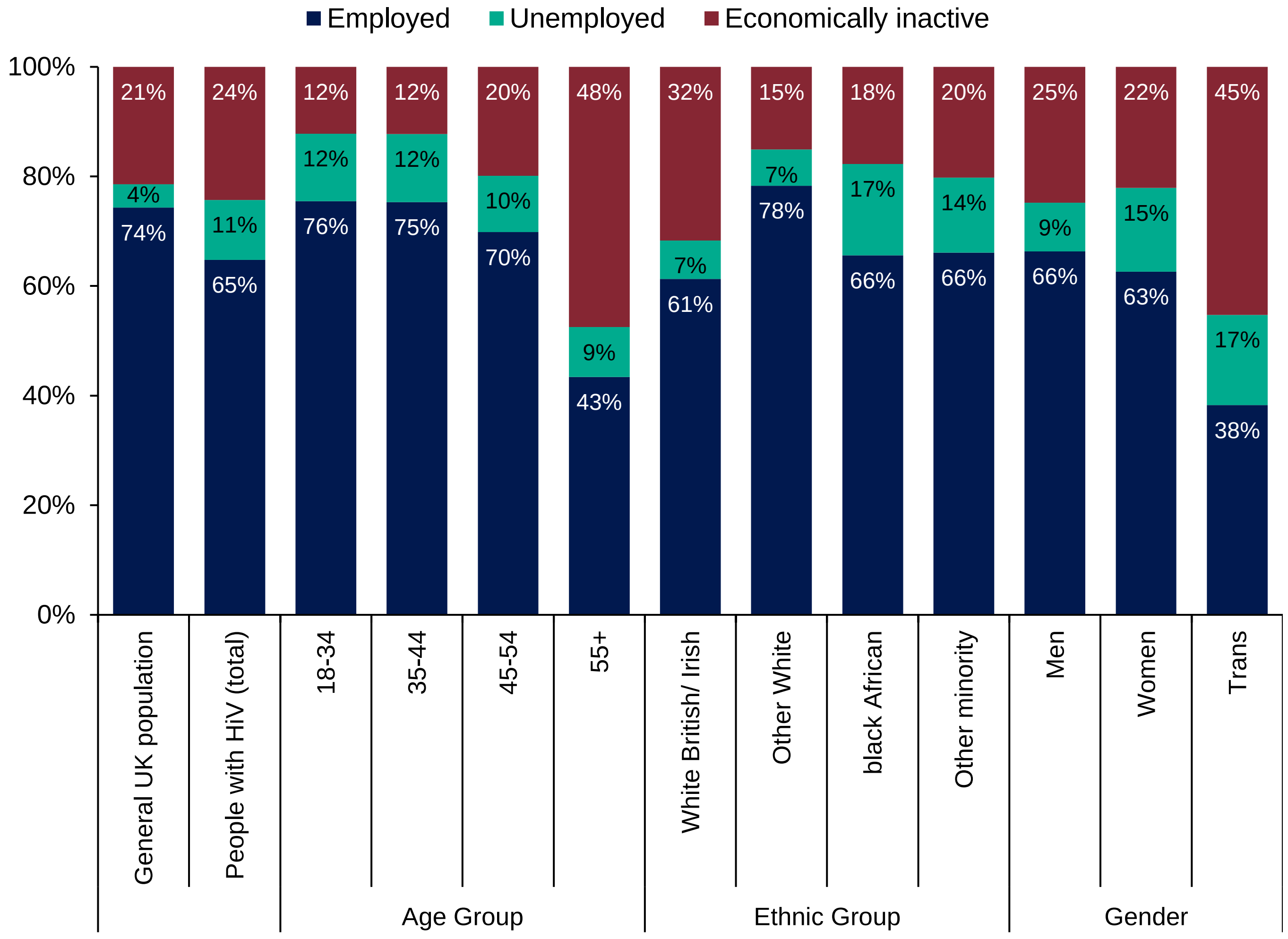
Unemployed: those able to work (not falling into economic inactivity category), but not currently employed.
Unemployment rate: those currently unemployed divided by those able to contribute to the economy (employed + unemployed) excluding those who are economically inactive.

Two-thirds (65%) of people with HIV were employed (including 52% full-time [at least 30 hours per week] and 13% part-time [less than 30 hours per week]) (Figure 36).

One in 4 (24%) were economically inactive, including 10% of people on long-term sick/disabled (for 3 months or more), 9% retired, 2% full-time student in education or training, 1% carers and 0.6% temporarily sick or disabled (for less than 3 months).

Overall, 11% of people with HIV were unemployed. After excluding those who were economically inactive when calculating the unemployment rate, this figure increased to 14%. Unemployment was higher in people with HIV in comparison to the general UK population over the same period (14% vs 4%)[16]. Slightly more people with HIV were economically inactive compared to the general population (24% vs 21%).

Figure 36: Employment status of people living with HIV



Within the HIV population, unemployment was highest among trans people (17%), people of black African ethnicity (17%) and other minority ethnicities (14%), women (15%) and younger adults (12% aged 18 to 34 and 12% aged 35 to 44).

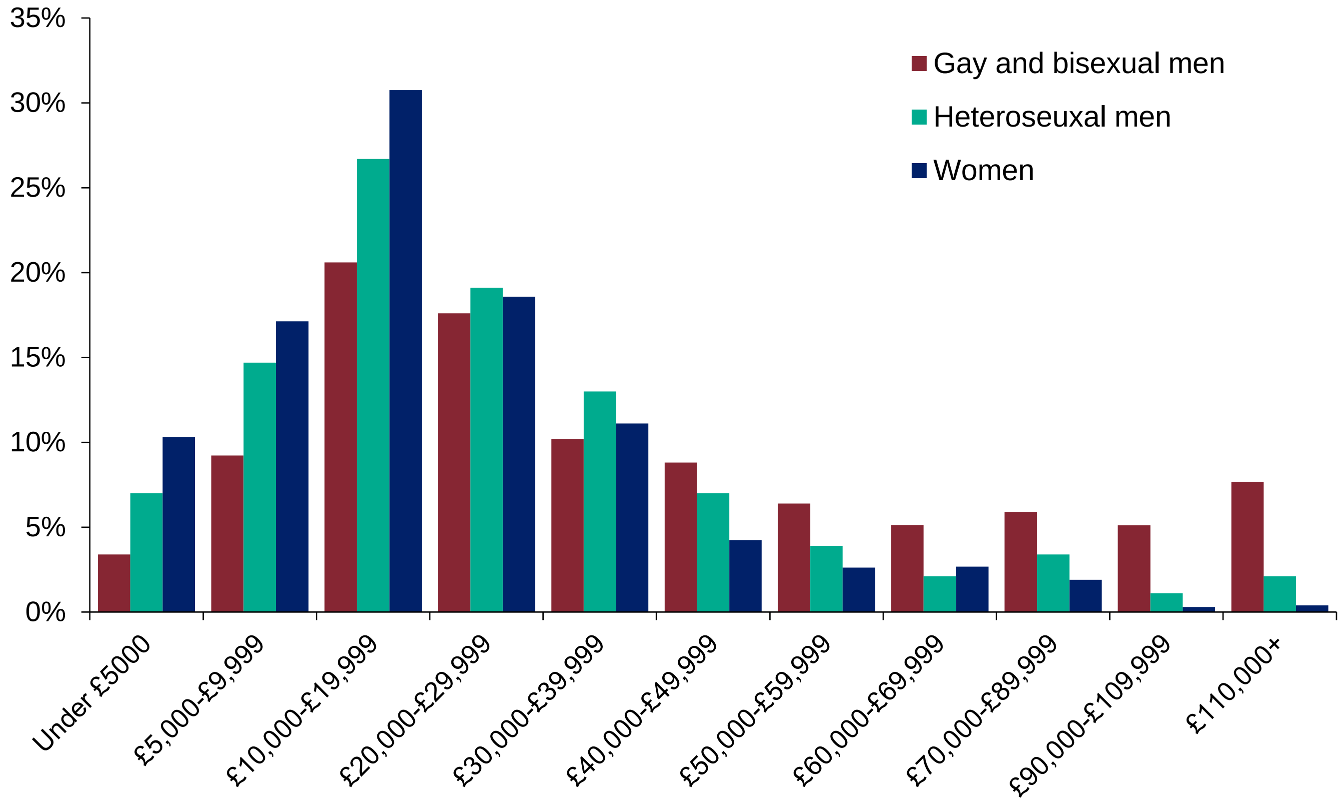
Household income

People with HIV were asked about their annual total household income before tax in the previous year. Household income is the combined income of everyone in the household, from all sources, before tax, including earnings from employment or self-employment, benefits, pensions, and other sources such as interest from savings[xxi].

Of those with income data, the median household income of people with HIV was between £20,000 and £29,000 (Figure 37). One in 6 (16%) had an annual household income of less than £10,000 and 21% had an income between £10,000 and £19,999.

The household income of people with HIV varied, with women twice as likely to have a household income less than £20,000 per year (58%) compared to gay and bisexual men (33%). Similarly, 57% of those of black African ethnicity had a household income less than £20,000 per year compared to 36% of those of white British/Irish ethnicity.

Figure 37: Total annual household income (before tax) of people with HIV



[xxi] The household income variable had the lowest completion rate in the survey at 76%. For 10% of participants this data was missing, 7% said they did not know and 7% preferred not to say.

Sources of income

> “I was very lucky that my housing association provided a care support worker who helped me for a year sort out my PIP and went to tribunal. Before it was awarded, I couldn’t pay bills, [and relied on] food banks.” Angela, 61

When asked to indicate all sources of income in the previous year, 66% of people with HIV reported receiving earnings from employment such as salary or wages and a further 6% receiving income from ad hoc, casual or consultancy work. One in 15 (7%) said they were primarily supported financially by their family and friends.

The receipt of welfare benefits was assessed from a list of 12 state benefits and tax credits. Overall, 28% were in receipt of a means-tested benefit (excluding Child Benefit) (38% of women and 24% of men) (Table 6).

The proportion of people with HIV in receipt of Disability Living Allowance (DLA) or Personal Independence Payment (PIP) was 15%; this increased to 41% among people who were diagnosed with HIV in the pre-highly active ART era between 1981 and 1995.

The most frequently reported means-tested benefits were housing benefit (13%) and Employment and Support Allowance (ESA) (13%). Overall, 28% of people with HIV were in receipt of one or more forms of welfare benefit (excluding Child Benefit), while 14% were in receipt of 2 or more benefits (Table 6).

Table 6: Receipt of welfare benefits by people living with HIV by age group, ethnicity and gender

Type of Benefit	People with HIV (total)	Age Group			Ethnic Group			Gender		
		18-34	35-54	55+	White	Black African	Other minority	Men	Women	Trans
Means-tested[1]	28.3%	20.7%	29.4%	29.6%	26.3%	32.6%	27.7%	23.7%	38.1%	44.1%
Disability benefit[2]	15.0%	4.8%	12.8%	24.9%	18.4%	9.0%	15.4%	15.9%	12.6%	26.7%

[1] Includes Universal Credit, Employment and Support Allowance (ESA) or Incapacity Benefit, Jobseeker’s Allowance (JSA), Income Support, Pension Credit, Tax Credits (Working Tax Credits and Child Tax Credits), Housing Benefit, National Asylum Support Service (NASS), and other state benefits.

[2] Includes Disability living allowance (DLA) or Personal Independence Payment (PIP)

Ability to meet basic needs

People with HIV were asked whether they had enough money to afford their basic needs (for example, food, rent, gas, electricity, water, etc) and the responses available were: “Yes, always”, “Yes, most of the time”, “Yes, some of the time”, and “No”.

Nearly half (47%) of people with HIV always had enough money to meet their basic needs. A further 26% stated that they had enough money most of the time, 14% some of the time, and 13% never had enough money for basic needs.

A much higher proportion of black African (76%) and people of other minority ethnicities (53%) reported that they did not always have enough money to meet their basic needs when compared to white British/Irish (39%). Likewise, 69% of women with HIV did not always have enough money to meet their basic needs in comparison to 46% of men.

Ability to keep up with bills

People with HIV were asked whether their household had beena keeping up with bills and credit commitments over the previous 12 months, and the responses available were: “Up to date with bills”, “Behind with some bills”, and “Behind with all bills”.

Overall, 70% of people with HIV were up to date with all their bills, 26% were behind in some of their bills, and 4% were behind with all of their bills.

Trends showed that older people with HIV were more up to date with bills when compared to younger people. Those of black African and other minority ethnicities were less likely to be up to date with bills in comparison to people of white British/Irish ethnicity (47%, 64%, and 81%, respectively).

> “If people with HIV can get financial assistance, it will help a lot. Like now, I'm working full time 28 hours a week. The money is not enough. I'm in pain. All my joints are painful. I can't get benefits.” Grace, 55

Met and unmet needs

> "HIV support services helped me positively in dealing with feelings of isolation. Gaining peer to peer support from others is immeasurable. Truly understanding that HIV is not a death sentence only came from meeting other survivors who have lived through the 80s. I only met these people through support services."
> Winston, 36

Use of HIV support services

HIV support services, such as charity or voluntary organisations, provide services that meet the physical, mental and emotional health needs of people with HIV that are apart from, but complementary to, clinical care.

Overall, 38% of people with HIV have used an HIV support service in the past; with 1 in 6 (16%) having used HIV support services in the previous year (Table 7). This proportion increased to 1 in 5 women (20%), trans people (20%), and black Africans (19%).

Of those who had used HIV support services, nearly all (92%) said they had been important to their health and well-being.

Table 7: Support service use and accessibility by geographical region

	Region of residence			
	London	South of England	Midlands, East of England & Wales	North of England
Have you had contact with an HIV charity or voluntary organisation, for any reason?				
No	62%	59%	67%	60%
Yes, in the last year	17%	17%	13%	18%
Yes, more than a year ago	21%	24%	21%	22%
Overall, how important would you say HIV support services have been for your health and wellbeing?				
Not at all	7%	9%	12%	8%
Slightly important	10%	12%	13%	17%
Moderately important	20%	18%	20%	20%
Very important	63%	61%	56%	56%

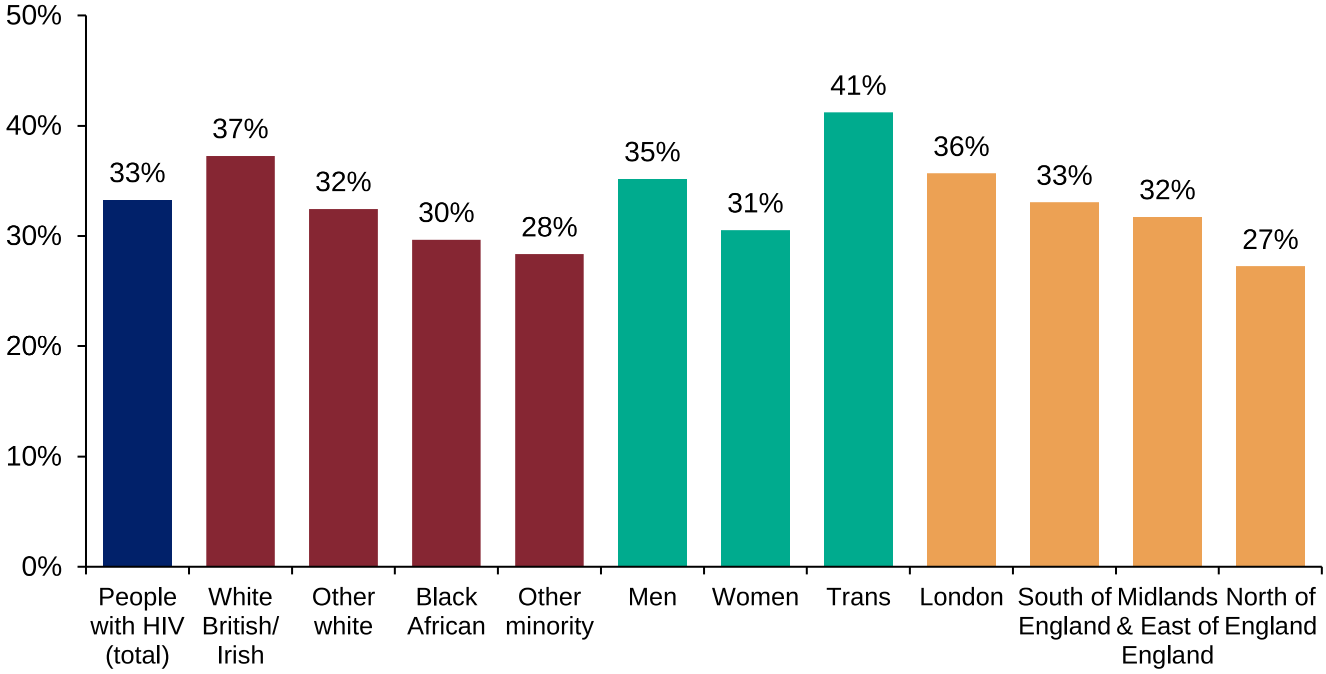
Access to HIV support services

> “Peer support doesn’t seem to be available where I live. There is little opportunity for support or social contact with other people with HIV. There seems to be lots in large cities but nothing in more rural areas.” Pascal, 62

Of those who had used support services, 1 in 3 (33%) of people living with HIV said that services had been become more difficult to access over the past 2 years (Figure 38).

There was some variation geographically, with Londoners (36%) more likely to say services had become more difficult to access compared to people in the North of England (27%).

Figure 38: Proportion reporting they found it more difficult to accessing HIV support services in the past 2 years, by age, ethnicity and gender



HIV-related service needs

> “The only people you can discuss your HIV condition with are staff at the HIV clinic. Nobody and no services exists to help you meet others with same condition. As an older patient the sense of isolation is higher.” Carl, 63

The needs of people living with HIV are diverse and the extent to which these needs are assessed, planned for, and met directly impact on the overall health and well-being of the patient.

The survey asked people whether people had used specific services (29 in total) in the previous 12 months, and whether or not they had received that service (Table 8). Services were split into 3 categories: HIV-related services (6), health-related services (11), and social and welfare services (12).

Table 8: Types of services or help included in the comprehensive needs assessment

HIV-related services	Information about living with HIV (including websites) HIV treatment advice Professional help to take your HIV tablets on time or correctly Peer support or social contact with other people with HIV Help disclosing your HIV status Long-term condition management support
Health related services	Psychologist or counsellor Help to manage stress Help to manage weight Help or advice regarding your sex life Help to stop smoking Alcohol counselling or treatment Drug counselling Chemsex support Drug detox or maintenance treatment Family planning or advice on getting pregnant Home health services
Social and welfare service	Housing support Meal or food services Childcare services Relationship advice Help dealing with loneliness or isolation Employment advice Career skills and training Help claiming benefits Financial advice Legal advice Immigration support Domestic violence services

The proportion of “need” was defined as the percentage of people with HIV who stated their need for a service, out of all those who responded to the question. The proportion of “unmet need” was defined as the percentage of people with HIV who did not receive it, out of those who stated they needed the service[xxii].

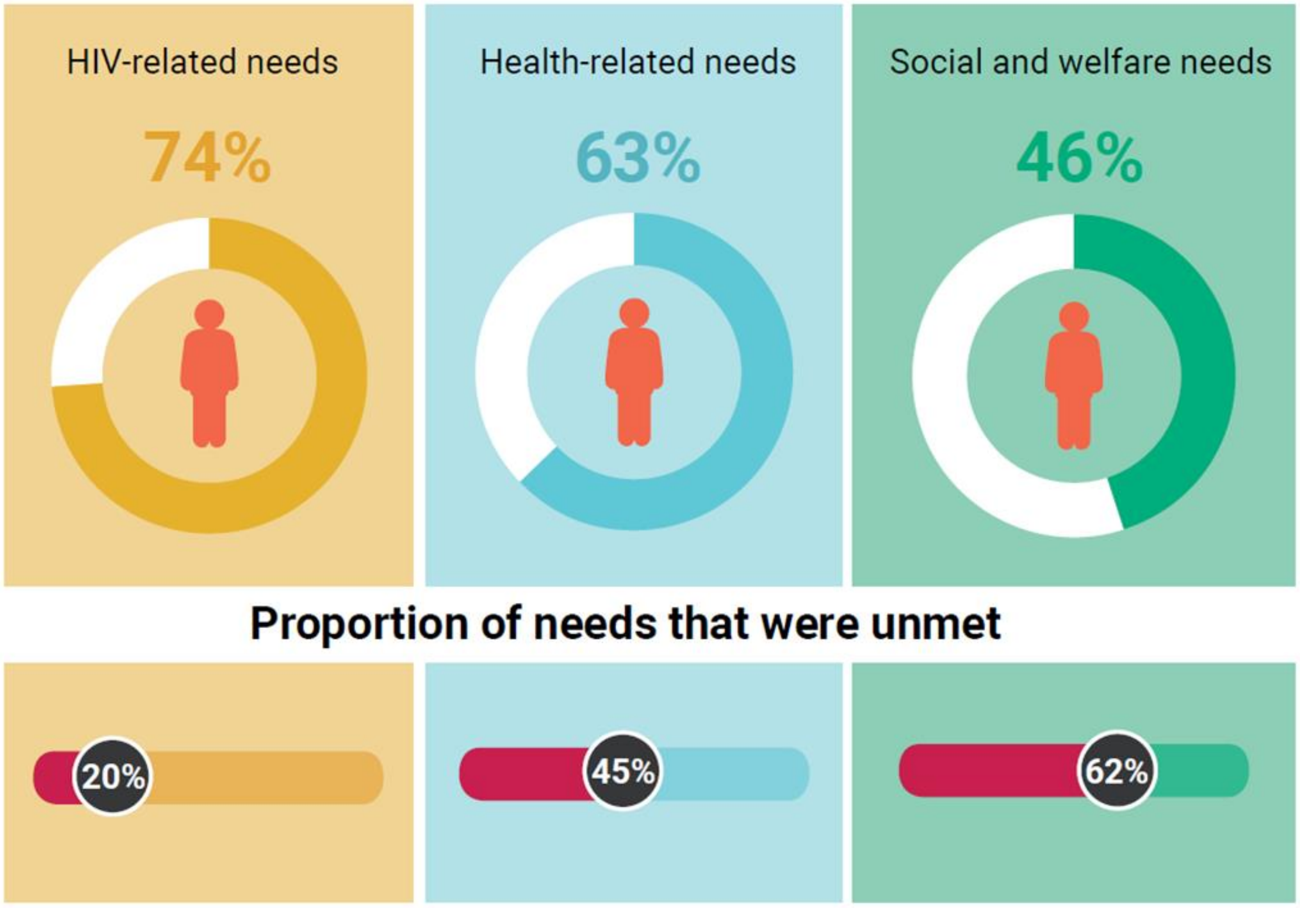
[xxii] In the survey, questionnaire responses in for service need included “I did not need this”, “I have received this”, “I needed this but could not get it” and “I needed this but did not try to get it”. Unmet need includes those who responded other of the last 2 options.

Figure 39 shows the results of a comprehensive needs assessment of people living with HIV. Unsurprisingly, three-quarters (74%) of people with HIV indicated they had one or more HIV-related needs in the previous 12 months. Around two-thirds (63%) of people had one or more of needs related to their health or lifestyle, and nearly half (46%) of people had one or more social and welfare needs.

Overall, HIV-related needs were mostly met, with 80% of the needs being indicated as met and only 20% of needs remaining unmet. Nearly half (46%) of all health-related needs were unmet. Social and welfare needs were mostly unmet, with 62% of people indicating that their needs had not been met in the previous 12 months.

Figure 40 illustrates the results of the needs assessment for the overall population of people with HIV. Figures 41 to 49 explores the results of the needs assessments for different HIV populations: by gender/sexual orientation (Figure 41: gay and bisexual men, Figure 42: heterosexual men and Figure 43: women), ethnicity (Figure 44: white British/Irish, Figure 45: other white [non-British/Irish] ethnicity, Figure 46: black African, and Figure 47: other minority [non-black African] ethnicities), and age (Figure 48: under 50 and Figure 49: over 50 years old).

Figure 39: Met and unmet HIV-related, health and social and welfare needs among people with HIV (in the previous 12 months)



HIV-related needs

The most commonly reported need overall was for HIV treatment advice Two-thirds (63%) the people with HIV indicated that they needed: of these, nearly all (93%) stated that they had received this advice. Similarly, 49% said they needed information about living with HIV: of these, 87% of this need was met.

In addition, 42% of people with HIV needed professional help to take their HIV tablets on time or correctly, and again 93% had received this help. One in 3 (33%) people with HIV said they needed peer support or social contact with other people with HIV; of these, nearly half (43%) said this need was unmet.

One in 4 (25%) of people living with HIV reported needing help disclosing their HIV status with others; this need was unmet for 40% of those who needed it. Additionally, services must adapt to respond to the complex health issues facing people with HIV into the future; 43% of people living with HIV said they needed advice on how to manage their long-term health conditions, and one-third (32%) reported this need was unmet.

Health needs

> “Depression and isolation is difficult to cope with and the facilities and social spaces available to HIV+ people are becoming more and more difficult to access. Funding is constantly being reduced for mental health and wellbeing. HIV-related stress is inevitable.” Claire, 61

The most commonly reported need was for stress management by 33% of people with HIV, of whom 53% did not have this need met. Similarly, 31% of people living with HIV needed a psychologist or counsellor in the previous year; of those, 38% did not see one.

Help managing weight was reported by 31% of people, and over half (53%) of people who reported this need said it was unmet. Help or advice regarding sex life was needed by 27% of people with HIV; but 40% did not receive it. One in 7 (14%) needed help to stop smoking, and nearly half (48%) of those who needed this support did not receive it.

Need for Drug and alcohol services were only needed by a relatively small proportion of people with HIV: 6% needing alcohol treatment or counselling, 6% needing drug counselling, 5% need chemsex support and 5% needing drug detox or maintenance. However, around half of these needs were unmet – the greatest of which was around chemsex support and drug detox (both 57% of need was unmet).

Social and welfare needs

> "With HIV, it seems difficult to acquire certain support that you need as those services do not seem to exist and, this withdraws you from asking for help that should be made available to you and your family." Maria, 41

Loneliness and social isolation is a recognised public health issue that can have serious consequences on health and quality of life. Among people with HIV, 21% needed help dealing with loneliness and isolation in the past year, but in three-quarters of cases (75%) this need was unmet: this was the greatest unmet need out of the 29 services assessed.

Housing support was needed by 23% of people with HIV and help claiming benefits by 20%, and around half of this need was unmet (48% for both). Much greater levels fof need were seen for other social services: 1 in 6 (16%) of people needed financial advice; of those, two-thirds (64%) of this need was unmet. Similarly, 15% required employment advice and 15% career skills and training, but most of this need was not met (63% and 69%, respectively). One in 11 (9%) needed meal or food services, and in 61% of cases this need was unmet.

Overall, 15% of people reported needing relationship advice in the previous year, but two-thirds of people (66%) said they did not receive the advice they needed. Three percent (3%) of people with HIV reported they needed support for domestic violence in the previous year; of these cases, only half (49%) received this support.

Figure 40: Met and unmet HIV, health, social and welfare needs of people living with HIV

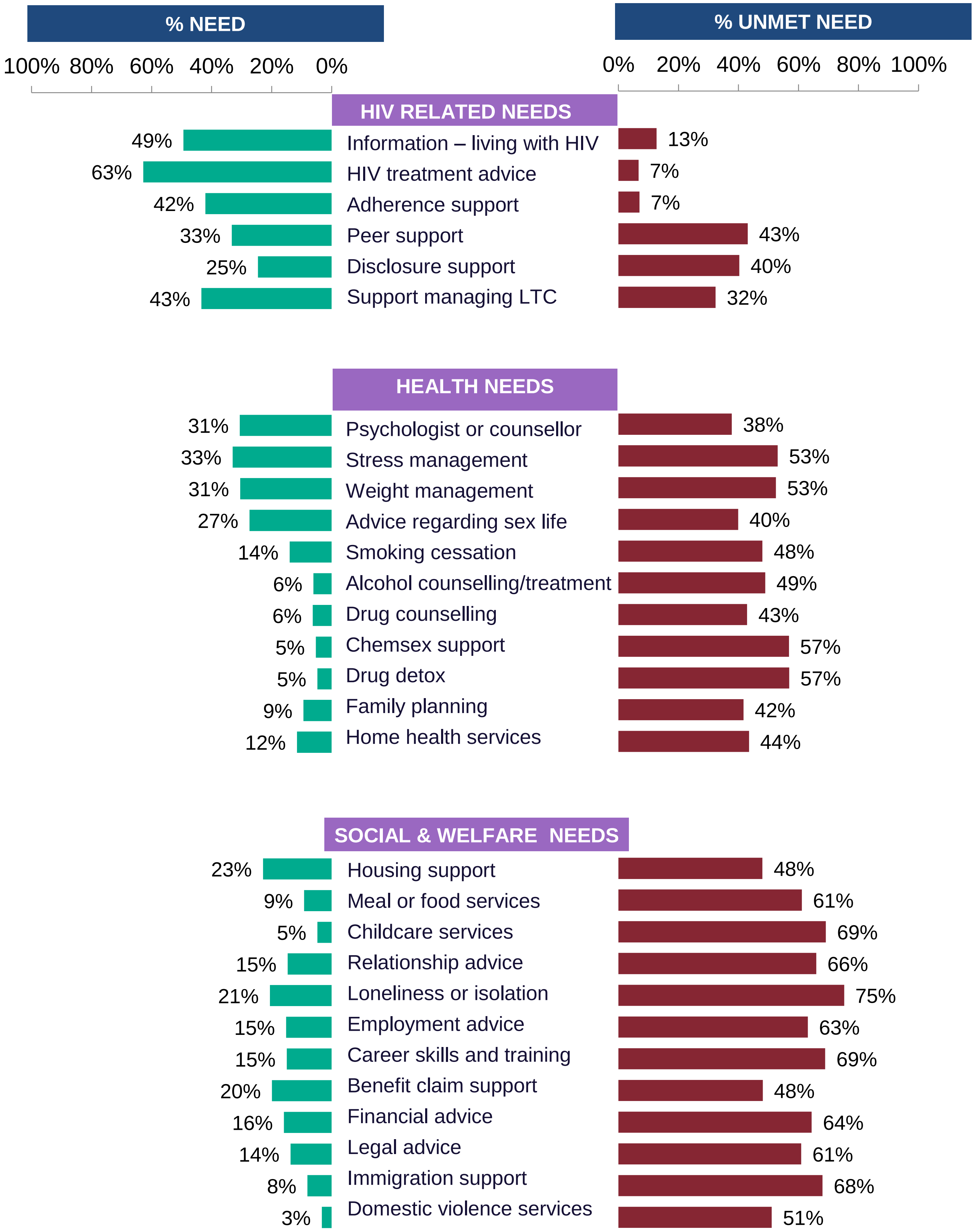


Figure 41: Met and unmet HIV, health, social and welfare needs of gay and bisexual men living with HIV

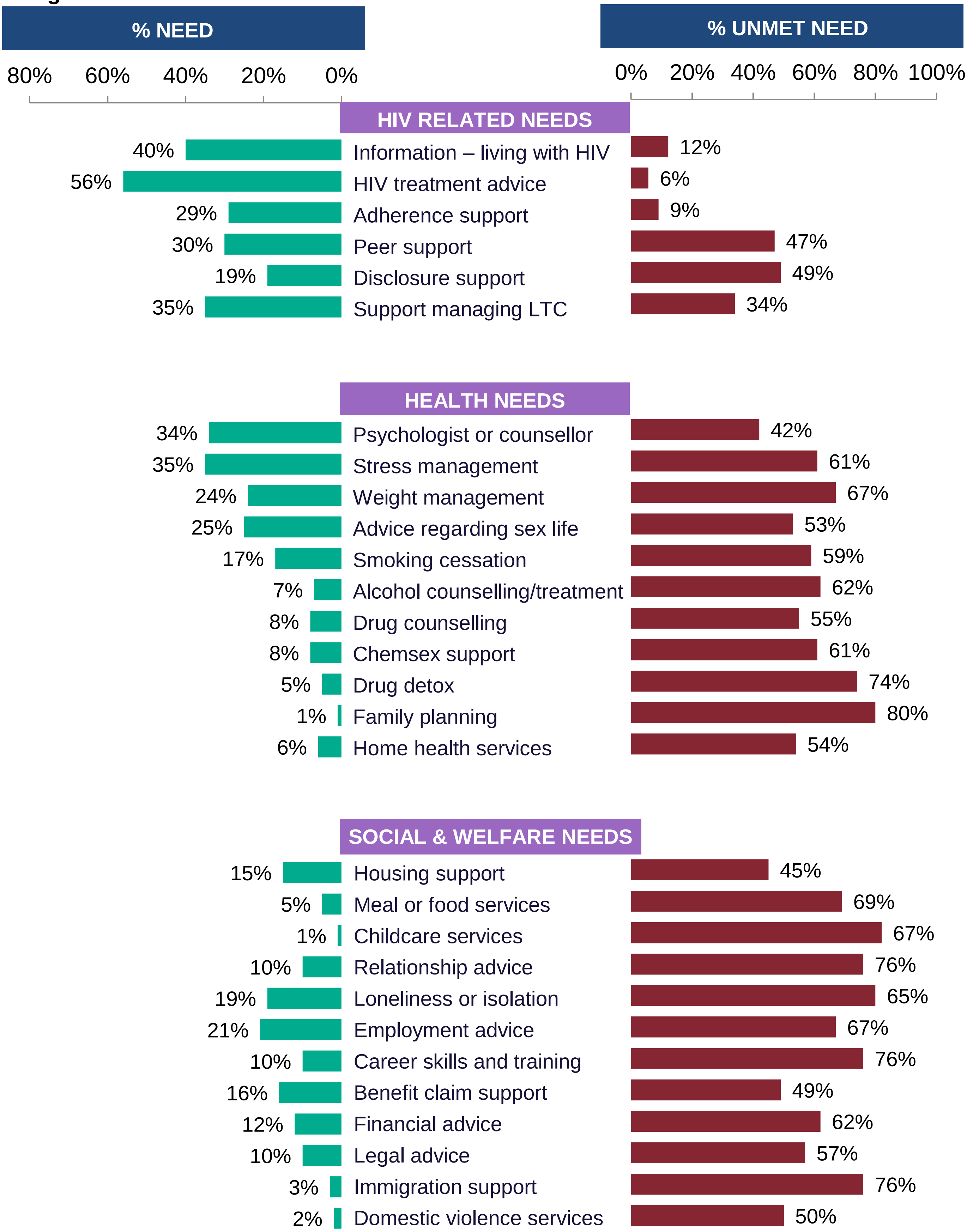


Figure 42: Met and unmet HIV, health, social and welfare needs of heterosexual men living with HIV

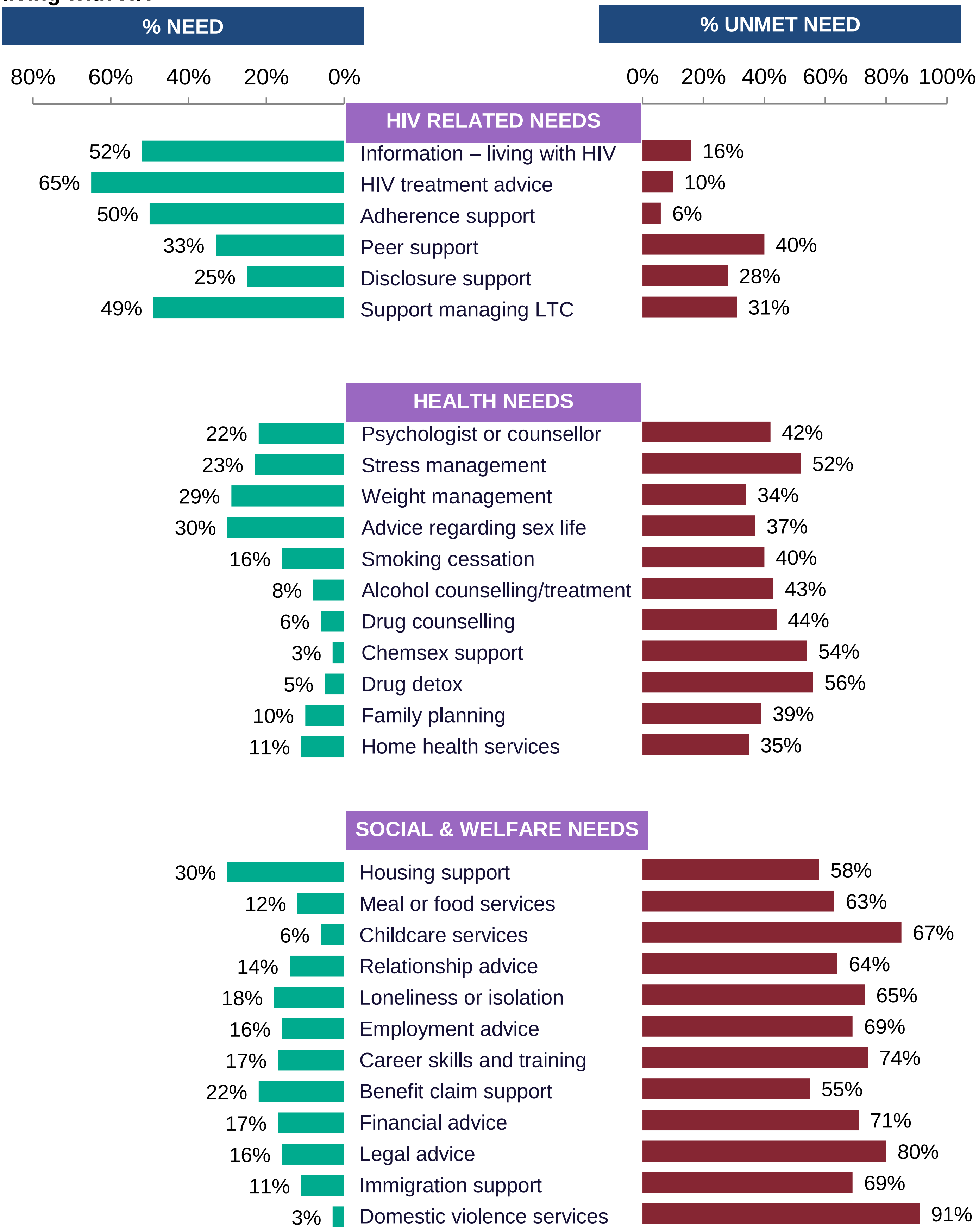


Figure 43: Met and unmet HIV, health, social and welfare needs of women living with HIV

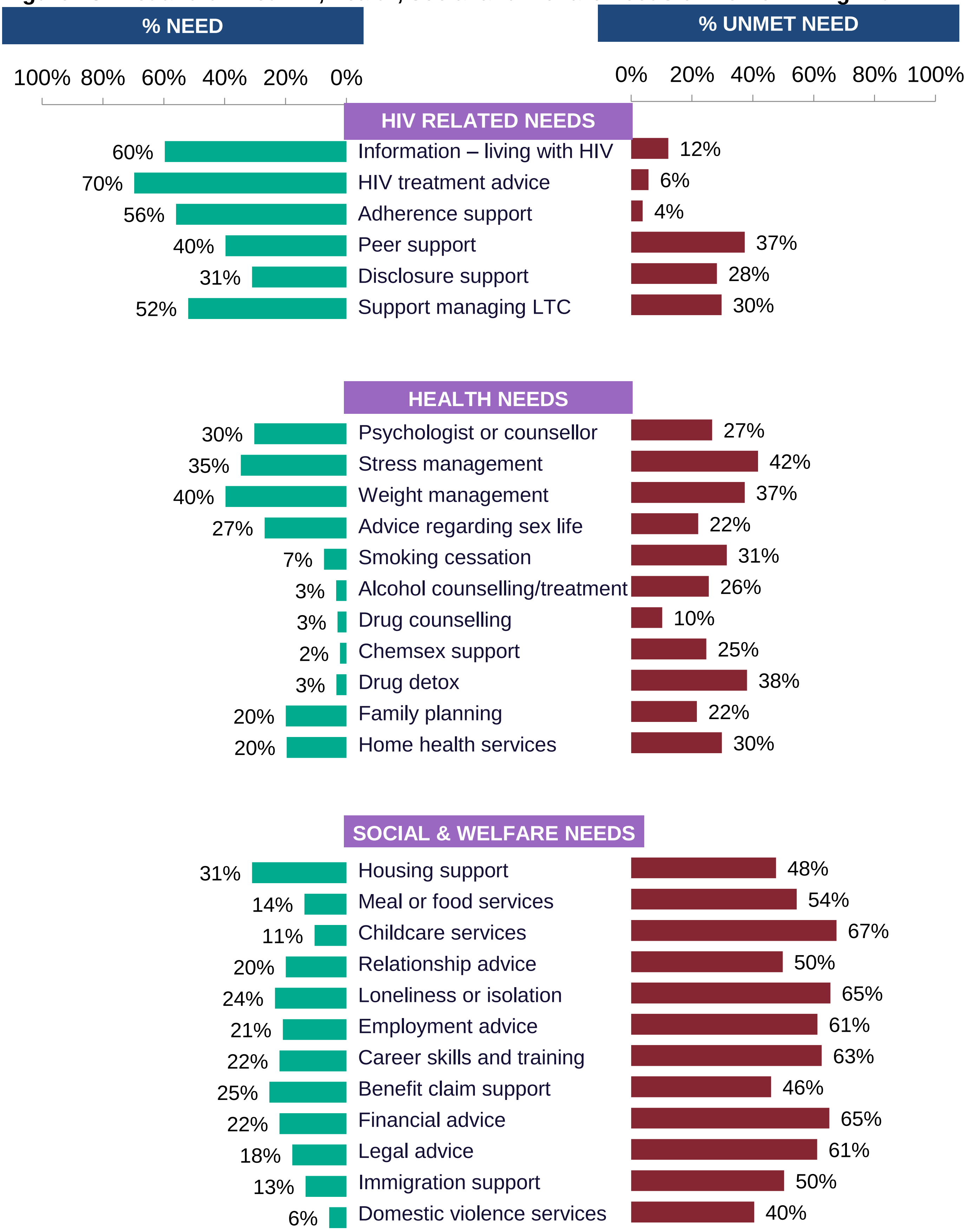


Figure 44: Met and unmet HIV, health, social and welfare needs of people of white British/Irish ethnicity living with HIV

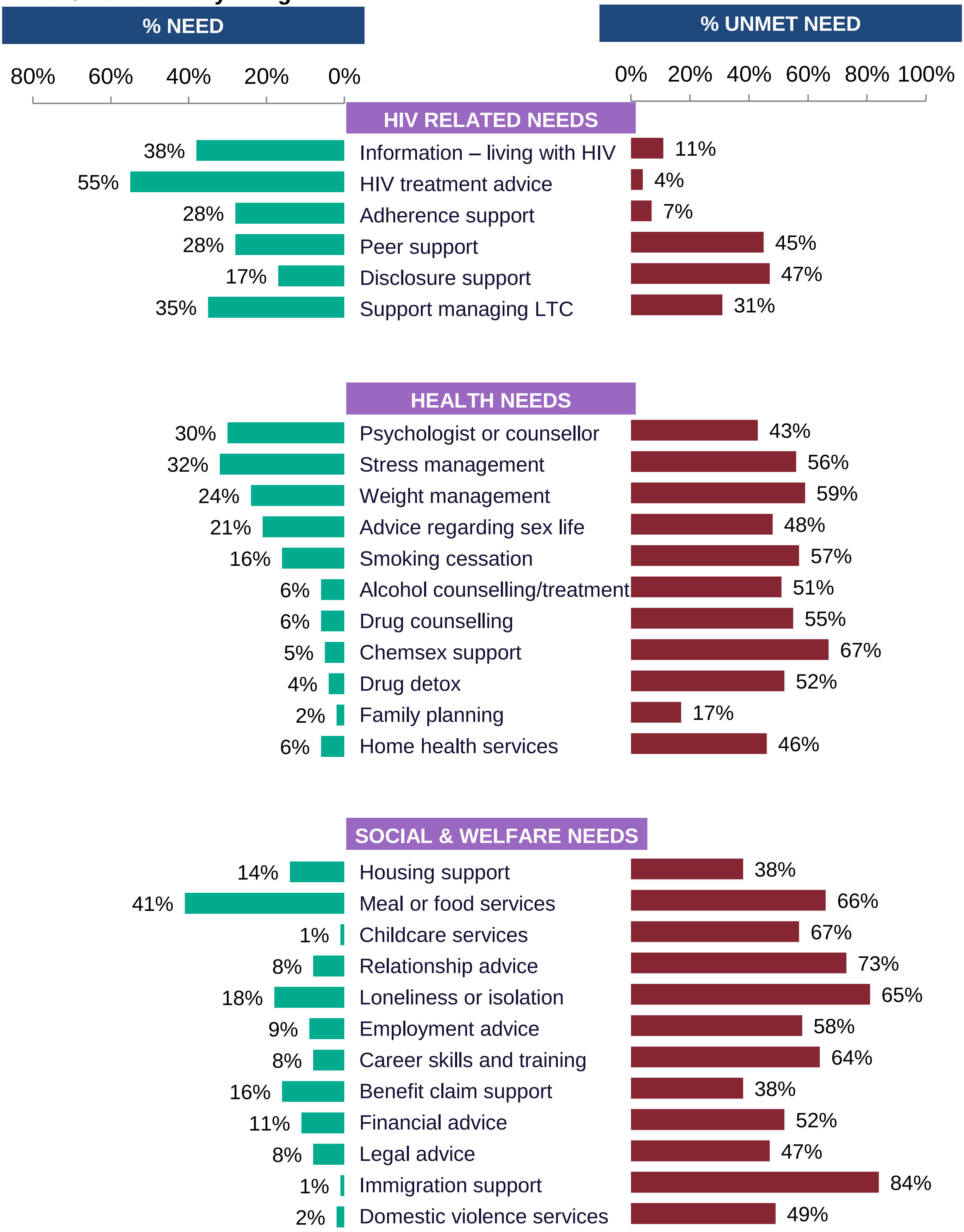


Figure 45: Met and unmet HIV, health, social and welfare needs of non-British/Irish white ethnicity living with HIV

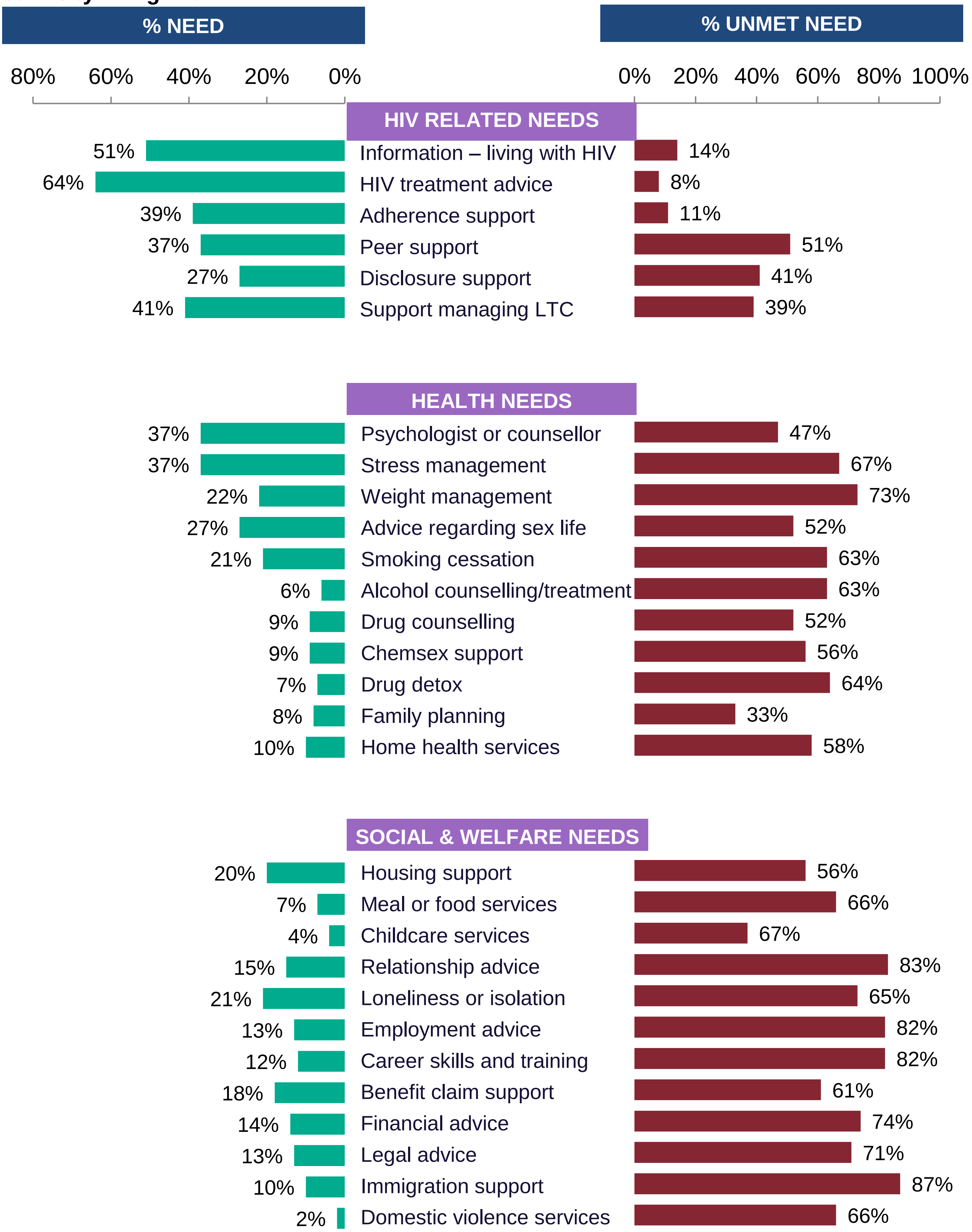


Figure 46: Met and unmet HIV, health, social and welfare needs of people of black African ethnicity living with HIV

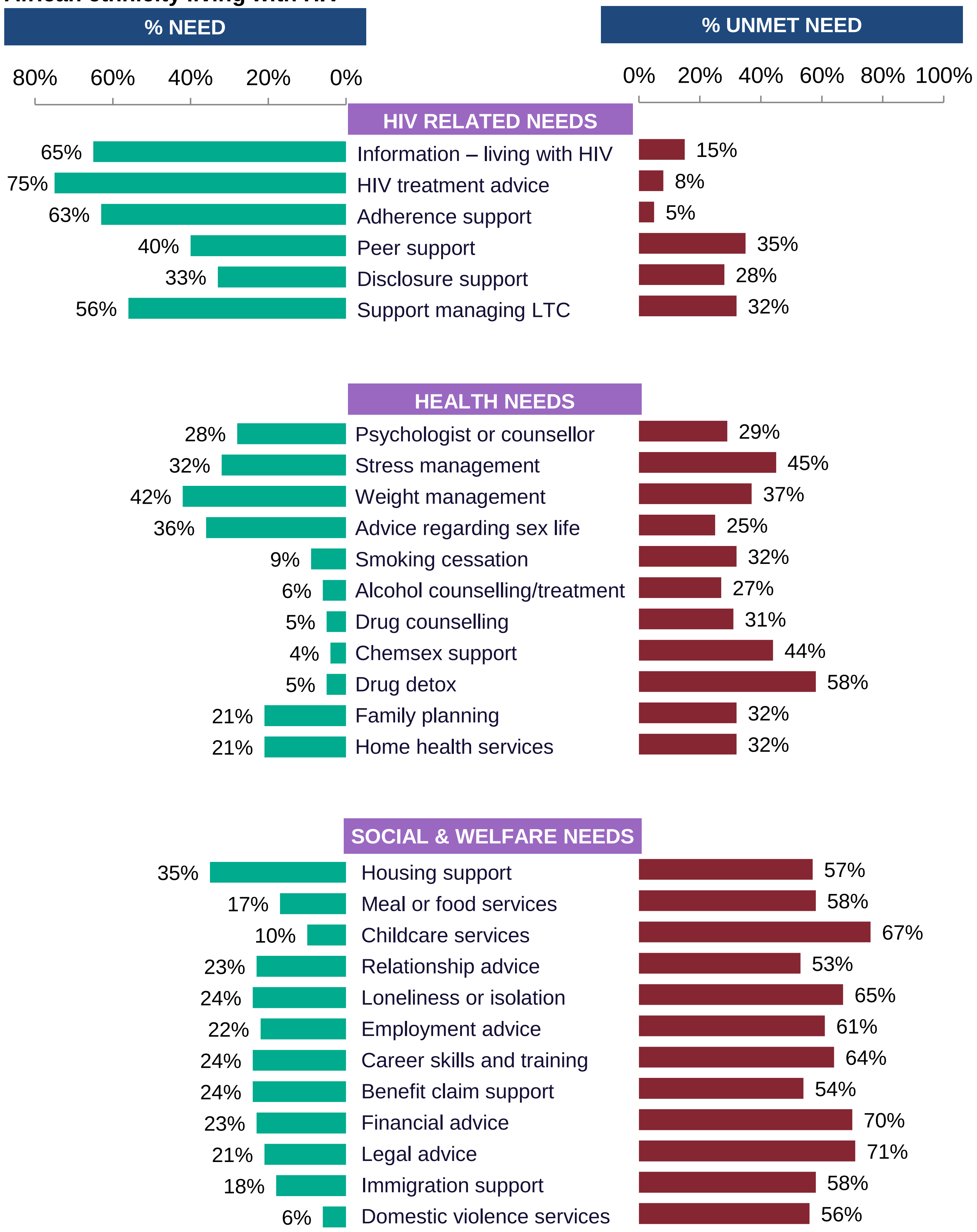


Figure 47: Met and unmet HIV, health, social and welfare needs of people of black and minority ethnicities (excluding black Africans) living with HIV

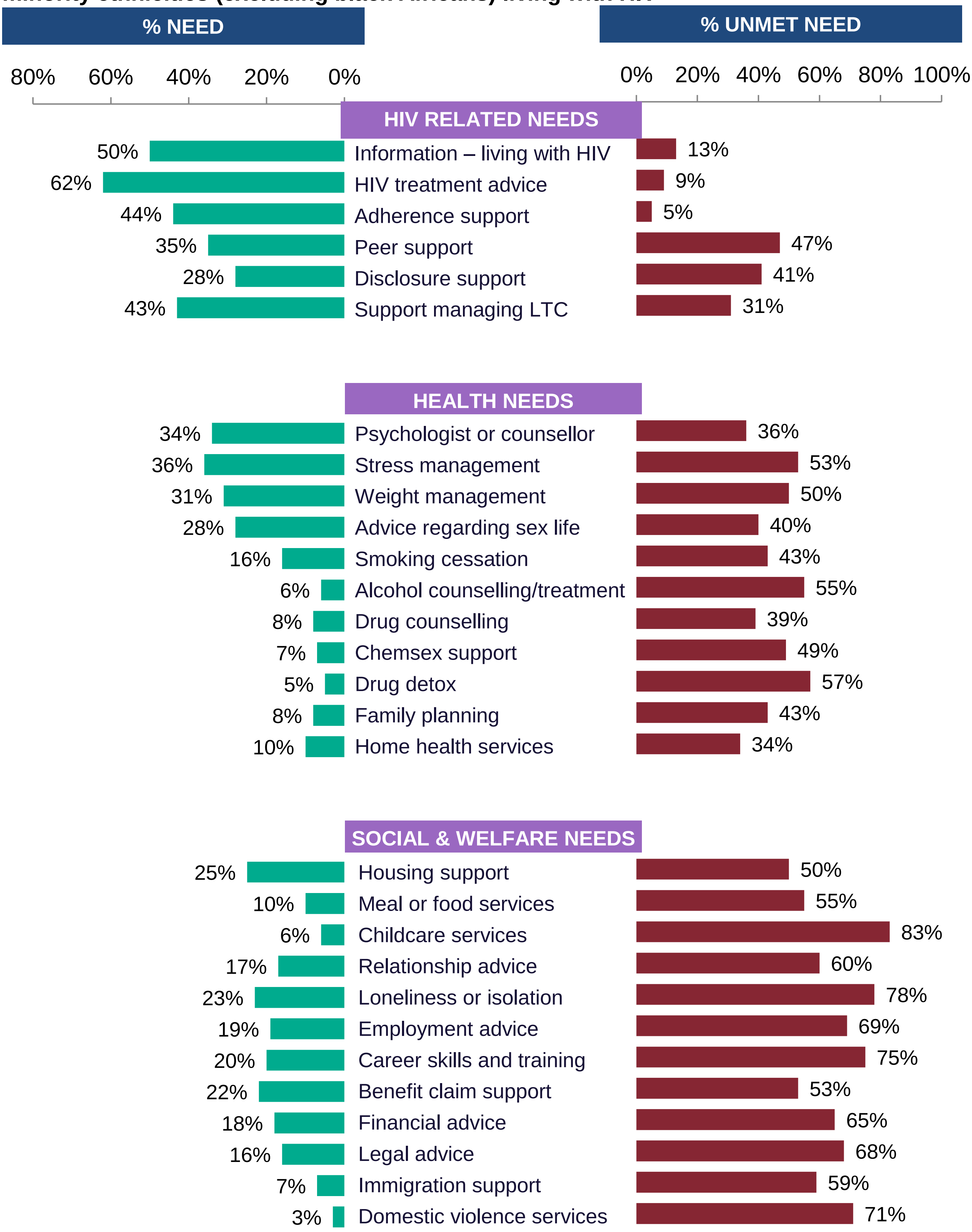


Figure 48: Met and unmet HIV, health, social and welfare needs of people aged under 50 years old living with HIV

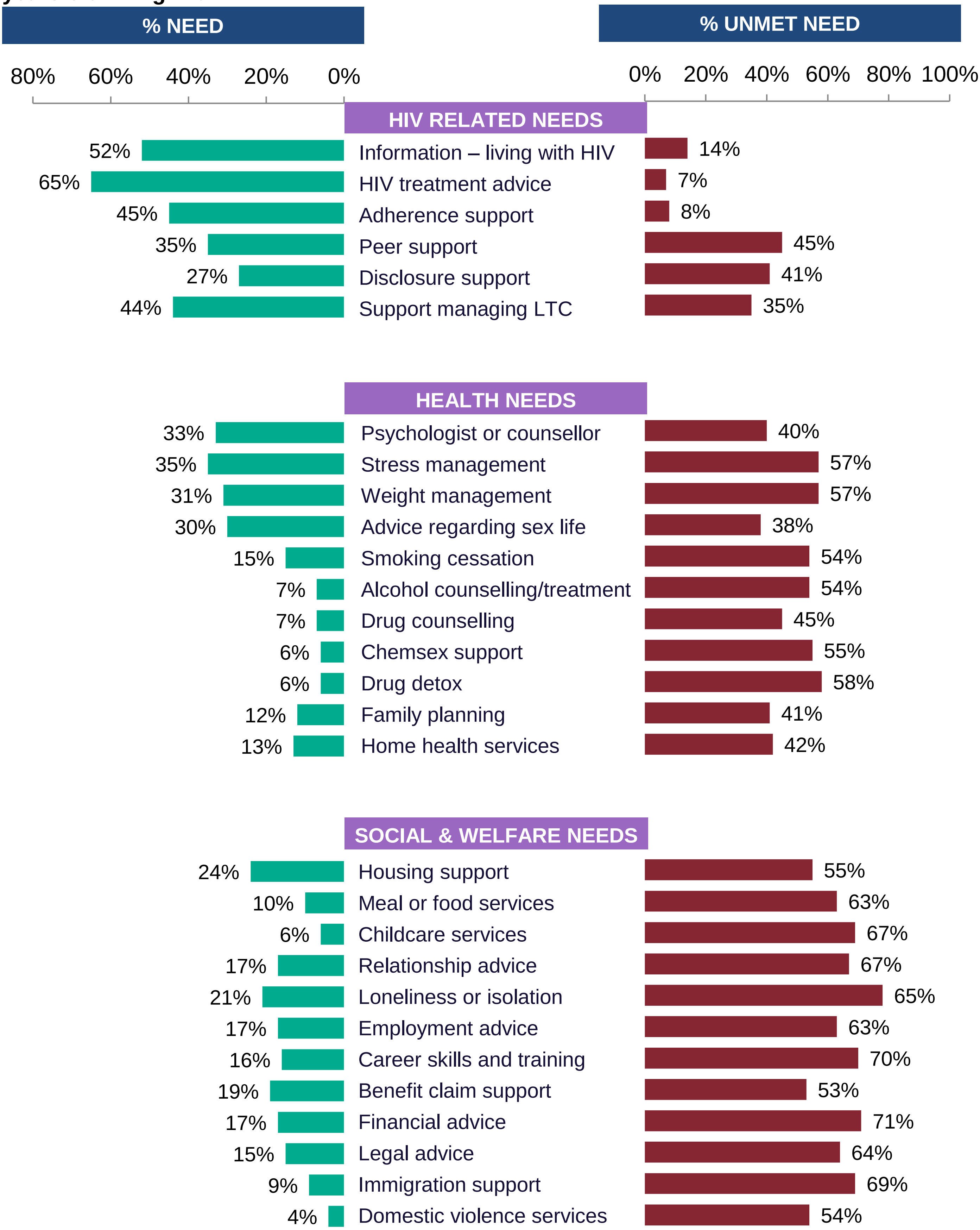
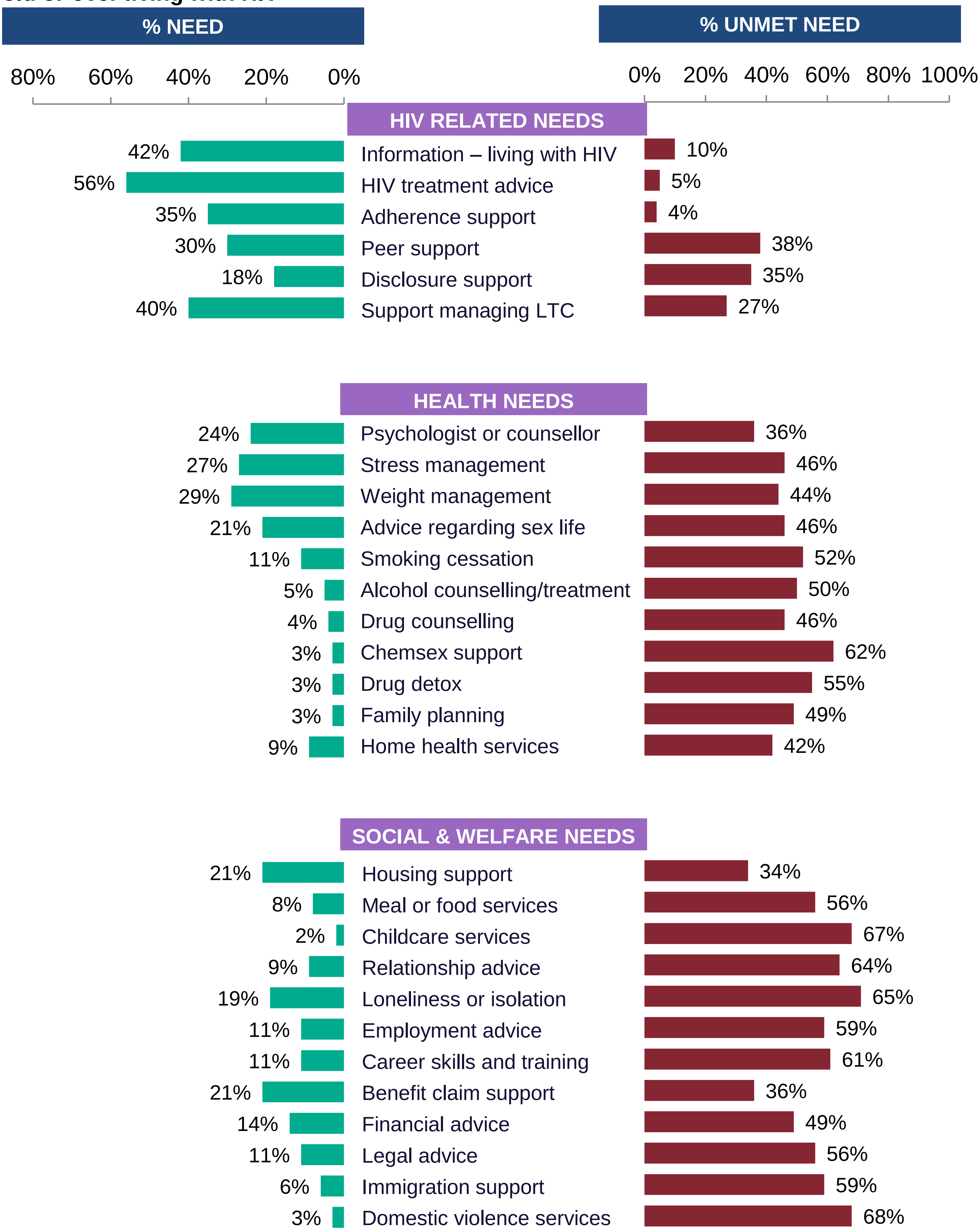


Figure 49: Met and unmet HIV, health, social and welfare needs of people aged 50 years old or over living with HIV



Appendix: Survey methodology

The method and questionnaire were developed with an Advisory Group of patient representatives, clinicians, academics, commissioners and civil society. An omnibus-style survey was designed using validated survey questions and instruments wherever possible to allow comparisons and tested through cognitive interviews with people with HIV (Appendix Table 1). Qualitative interviews with HIV patients and clinic staff identified the most feasible, acceptable, and sustainable methods to implement the survey and recruit participants. In 2014, the survey was piloted in 30 HIV clinics. Survey metadata were collected (eg. reasons for non-recruitment, implementation issues flagged by clinics) to inform methods for the national survey

Appendix Table 1: Positive Voices survey topics and questions

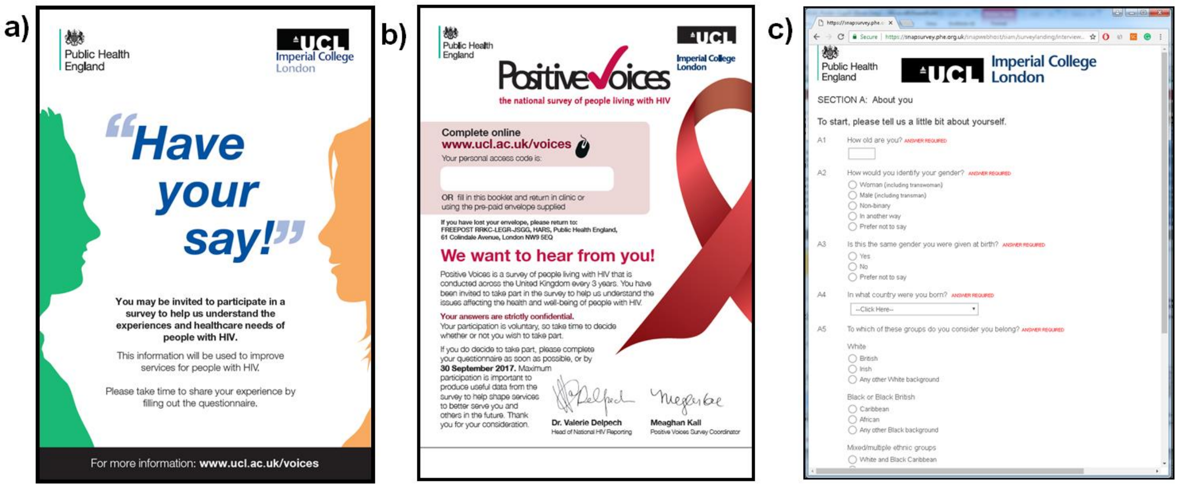
Topic	Survey Questions
HIV diagnosis and treatment	HIV diagnosis facility, ART adherence (ACTG-14 day), side effects
Comorbidities	Ever diagnosed health conditions & co-infections, year/age of diagnosis and non-ART medication
Health and Wellbeing	Life satisfaction (ONS), health status (SF-36), quality of life (EQ-5D-5L), generalised psychiatric disorders (GHQ-12)
Stigma & Discrimination	Disclosure, discrimination in healthcare settings
Sex & Relationships	Sexual history (main and casual partners), STI diagnoses, women’s sexual and reproductive health
Lifestyle	BMI, smoking, alcohol and drug use, injecting history
Service Use & Satisfaction	GP and HIV service use and satisfaction, patient experience measures, use of HIV support services
Sociodemographic	Employment and income, education, housing, religion, sexual orientation
Met and Unmet Needs	Need for and receipt of HIV related services, health services, social and welfare services in previous year

Sampling frame

The HIV and AIDS Reporting System (HARS) the UK's comprehensive national HIV cohort and surveillance dataset was used as a sampling frame. HARS is a consultation based, disaggregate dataset which is submitted on a quarterly basis, and reported by all outpatient HIV service providers in England, Wales and Northern Ireland. www.gov.uk/guidance/hiv-surveillance-systems

A two-stage sampling design was used: (1) All HIV clinics in England and Wales reporting ≥5 patients in 2015 were invited to take part (2). A random sample of patients was drawn from the 2015 attendance list of participating clinics (based on clinic size). Patients were approached by local hospital staff in person, by post or by email. Surveys were self-completed on paper or online (Appendix Figure 1). Paper surveys could be returned in clinic or via a Freepost envelope included in the survey pack and an unconditional £5 high street voucher was included as an incentive.

Appendix Figure 1: (a) Promotional poster placed in clinics; (b) paper format of survey; (c) online format of survey



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"Have your say!"

You may be invited to participate in a survey to help us understand the experiences and healthcare needs of people with HIV.

This information will be used to improve services for people with HIV.

Please take time to share your experience by filling out the questionnaire.

For more information: **www.ucl.ac.uk/voices**

Public Health England
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Positive Voices
the national survey of people living with HIV

Complete online
www.ucl.ac.uk/voices
Your personal access code is:

OR fill in this booklet and return in clinic or using the pre-paid envelope supplied

If you have lost your envelope, please return to:
FREEPOST RRKC-LEGR-JSGG, HARS, Public Health England,
61 Colindale Avenue, London NW9 5EQ

We want to hear from you!

Positive Voices is a survey of people living with HIV that is conducted across the United Kingdom every 3 years. You have been invited to take part in the survey to help us understand the issues affecting the health and well-being of people with HIV.

Your answers are strictly confidential.
Your participation is voluntary, so take time to decide whether or not you wish to take part.

If you do decide to take part, please complete your questionnaire as soon as possible, or by **30 September 2017.** Maximum participation is important to produce useful data from the survey to help shape services to better serve you and others in the future. Thank you for your consideration.

Dr. Valerie Delpech
Head of National HIV Reporting

Meaghan Kall
Positive Voices Survey Coordinator

https://snapsurvey.phe.org.uk/snapwebhost/siam/surveylanding/interview...

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SECTION A: About you

To start, please tell us a little bit about yourself.

A1 How old are you? ANSWER REQUIRED

A2 How would you identify your gender? ANSWER REQUIRED
○ Woman (including transwoman)
○ Male (including transman)
○ Non-binary
○ In another way
○ Prefer not to say

A3 Is this the same gender you were given at birth? ANSWER REQUIRED
○ Yes
○ No
○ Prefer not to say

A4 In what country were you born? ANSWER REQUIRED
--Click Here--

A5 To which of these groups do you consider you belong? ANSWER REQUIRED

White
○ British
○ Irish
○ Any other White background

Black or Black British
○ Caribbean
○ African
○ Any other Black background

Mixed/multiple ethnic groups
○ White and Black Caribbean

Data Collection

Data collection involved several processes including a separate recruitment of participating HIV clinics and the recruitment of a random selection of patients (survey participants) who had attended the participating clinic during 2015.

12,114 patients who had attended the participating clinics were randomly sampled using the HARS database archive (data to December 2015). The sample equated to approximately 20% of patients seen at each clinic in 2015.

Recruitment of participants ran from January to September 2017. Overall, 8,463 (70%) patients had attended the clinic over this time or were successfully contacted by clinic staff to take part in the survey. 4,422 of invited patients completed the survey, leading to a 52.3% response rate. Most participants (87%) chose to complete the survey using the paper questionnaire and 13% completed the survey online.

Paper questionnaires were entered electronically by hand one time and uncertainties were flagged for further review. Most uncertainties included issues around unclear handwriting, multiple ticked boxes, and answers that did not follow instructions within the survey. The study team reviewed all queries flagged during data entry and tried to make sense of illegible responses and non-sensible answers (ex. year of diagnosis stated before the HIV epidemic began, or a height of 10 feet). When a definitive answer could not be reached about a query, the question was left blank or data was replaced to missing. Handwriting illegibility was not an issue for online surveys, but similar methodology was applied to all data, regardless of format.

Data cleaning

Data from the paper format was merged with data from the online version of the survey. During data cleaning, categorical variables were coded such that each category corresponded to a numeric value (ex. men=0 / women=1 / non-binary=3). Throughout the entire questionnaire, when routing was incorrectly followed, answers that should have been routed around and not answered were replaced to missing (ex. men (not transmen) who answered the women’s reproductive health section). When routing was instructed but answers did not follow instructions, data was sensibly replaced (ex. if the participant did not tick “Yes” to “Do you have a main partner” but answered all of the following questions on main partners, “Do you have a main partner” was replaced to “Yes”).

For variables that were derived using several survey questions, such as adherence (used questions on current ART medication, daily number of tablets taken, and number of tablets missed in the previous 2 weeks) if any one question involved in the equation had missing data, the derived variable was also missing.

In the section of the survey focused on other non-HIV health conditions and medications, rarer conditions were reported in free text. Quite a few free text conditions were provided, some of which were not necessarily chronic health conditions (ex. “I once broke my arm”). Clinicians assisted with a condition verification process so that an accurate number of “other” conditions could be reported. Free text responses for each “other” health condition category (cardiovascular, joint and bone, mental health, and other long-term) were given to 2 clinicians who specialised in HIV and sexual and reproductive health. Clinicians decided if the free text response was a valid “other long-term condition” and provided justification for their decision. Agreement was compared between each clinician who validated the same set of free text responses. When they clinicians did not agree, further steps were taken to make a final decision.

For example, if one clinician said “no” and the other said “unsure / not enough information,” the final verdict was “no, not a long-term condition” as not enough information was provided by the participant to make a conclusive decision. When one clinician said “no” and the other said “yes,” further clarification was obtained. When a free text response listed a specific medical procedure but did not state any supporting information about the underlying cause of the procedure, it could not be assumed that there was an underlying disease and this data was replaced to missing.

Highest educational attainment was collected and aligned to match the ISCED 2011 educational framework in order to standardise educational levels for those who completed schooling overseas. Justification for choosing this framework stems from its differentiation for tertiary education in line with the European Qualification Framework (EQF) and the Bologna Process. This framework is comprised of 8 levels that were aligned with the educational levels in the Positive Voices survey. Current employment status was aligned to mirror the Office for National Statistics (ONS) measurements of employment and economic activity (Office for National Statistics, 2019).

Linking to national HIV & AIDS reporting system All surveys were given a unique 6-digit passcode. This passcode could then be matched back to national surveillance records.

Weighting

Sampling weights were applied to account for unequal probability of selection by applying 2 different sets of weights: (1) clinic weight, Pr(clinic), a constant which corrected for the selection of the 73 participating clinics out of the 180 eligible HIV clinics across England and Wales; and (2) person weight, Pr(patient), which corrected for unequal probability of selection of a patient from the eligible patients within each of the participating clinics. Therefore, the final sampling weigh applied is as follows:

Weight = 1 / Pr(clinic) * 1/Pr(patient)

The following variables informed the weighting strata to transform the raw survey data into a finalised weighted dataset that produces estimates that are generalisable for all people accessing HIV care in England and Wales:

Gender

- 0 = men
- 1 = women and other genders

Probable exposure route

- 0 = Sex between men

- 1 = All other exposure routes

Ethnicity

- 0 = White British/Irish
- 1 = Black African
- 2 = All other ethnic groups

Age

- 0 = ages 18-34
- 1 = ages 35-54
- 2 = ages 55+

Region of residency

- 0 = London
- 1 = outside London

A total of 54 strata were created such that observed estimates of each of the above variables were compared to actual proportions of all people accessing HIV care in 2017, using the HARS national database as a reference. From here, a weighting algorithm was deployed to align the observed Positive Voices proportions with the actual HARS proportions. Due to low numbers, the age strata for [non-gay and bisexual men, Outside London, Other Ethnicity] were slightly adjusted to (18-39 years, 40-49 years, 50+ years).

Analysis

All analyses were conducted in Microsoft Excel and STATA 13.0.

Note on general population comparisons

Wherever possible, general population comparisons from other national surveys were sought to provide context to interpret the findings for people living with HIV. The primary sources were:

- Health Survey for England (2017) – England only
- Office for National Statistics Health and Lifestyle Survey (2017) – UK-wide
- Office for National Statistics Labour Force Survey (2017) – UK-wide

Geographically, the survey included residents of England (n=4,353) and Wales (n=69). However, some general population comparisons presented are for England only. This was necessary for 2 reasons. Firstly, due to small numbers in Wales it was not possible to present reliable disaggregate data for Wales only. Secondly, in some but not all instances a general Welsh population comparator was not available. General UK population data were preferred over England only data.

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