# UNITED KINGDOM

## Statistical data

Population size of the country was estimated at 67.886.000[193] (year 2020).

Estimate number of PLHIV is 106.890.

The state of the 90-90-90 treatment target in 2020[194] was as follows:

- Percentage of PLHIV diagnosed (first 90 target): 95 %
- Percentage of PLHIV on treatment (second 90 target): 99 %
- Percentage of PLHIV with undetectable viral load (third 90 target): 97 %

## Main epidemiological trends[195]

In 2020, 2.780 new HIV cases were diagnosed in the UK, equivalent to 4,1 new cases per 100.000 inhabitants. Compared to 2019, the number of all new HIV diagnoses decreased by 33 %.

Due to the COVID-19 pandemic, data for Scotland for 2020 is unavailable and data completeness and quality were compromised in other areas of the UK. Consequently, the HIV annual report of 2020 focuses primarily on England.

In England, the equivalent figure was 2.630 (new cases). Out of the new cases reported in England, 70,7 % accounted to men. 45,3 % of the new diagnoses were attributed to gay and bisexual men. London continues to have the highest rates of HIV in England: 37% of new diagnoses in 2020 were in London residents.

Late HIV diagnosis presents itself as a problem especially among heterosexual men and women. In 2020, 670 new diagnoses (among people first diagnosed in the UK) were made at a late stage of infection in the UK. Figures show that 55 % and 51 % of heterosexual men and women respectively were diagnosed with a low CD4 count; in comparison, only 29 % of gay and bisexual men were diagnosed at a late stage of the infection.

Only 3 % of people diagnosed with HIV in the UK in 2019 had contracted HIV via injecting drug use; New diagnoses among people who inject drugs remained stable and low. However, an outbreak of HIV in Glasgow (Scotland) among people who inject drugs that started in 2015 has been persistent.[196] There is new evidence to suggest that this outbreak has now extended beyond Glasgow into other UK populations.

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[193] UN Department of Economic and social Affairs, Population Division. *World Population Prospects 2019*. Available at: https://population.un.org/wpp/Download/Standard/Population/

[194] UK Health Security Agency. *HIV testing, new HIV diagnoses, outcomes and quality of care for people accessing HIV services: 2021 report*. Available at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1037215/hiv-2021-report.pdf

[195] Ibid

[196] National AIDS Trust. *HIV Outbreak in Glasgow*. Available at: https://www.nat.org.uk/sites/default/files/HIV_outbreak_in_glasgow_1.pdf

## Relevant anti-discrimination legislation applicable in healthcare settings

The UK has no formal written constitution that can overturn legislation. Individual rights are protected in the courts, which balances these rights with respect for the sovereign law-making authority of the Parliament. However, the Human Rights Act incorporates most of the rights and freedoms contained in the European Convention on Human Rights (ECHR), and the UK respects the European Court of Human Rights.

The Human Rights Act[197] prohibits discrimination in Article 14 which provides that the enjoyment of the rights and freedoms shall be secured without discrimination on any ground such as sex, race, colour, language, religion, political or other opinion, national or social origin, association with a national minority, property, birth, or other status. It is not entirely clear whether the open-ended nature of this list through the inclusion of "other status" shall ensure that protection against discrimination is also provided to PLHIV.

In late 2021, the UK Government commenced a public consultation regarding possible changes to the Human Rights Act, which has raised some concerns among local human rights activists as potential changes may be to the detriment of human rights.

The Equality Act 2010[198] (which applies in England, Scotland and Wales, but not Northern Ireland) protects individuals who fall under nine protected characteristics from discrimination by employers, providers of goods and services (including healthcare services, whether publicly or privately provided) and public bodies. One of the nine protected characteristics is disability, and people automatically meet the disability definition from the point of diagnosis if they have HIV (also cancer and multiple sclerosis).

People cannot be asked about disability or health conditions in relation to the provision of goods and services, except where that may be done to protect the person receiving the goods or services (i.e. if provision of goods or services would put you at risk because of your health condition). This has, for example, been an issue in the UK in relation to tattooing and beauty parlours, where practitioners refuse to provide the service to PLHIV.

There is also a duty on public bodies to have due regard for the need to eliminate unlawful discrimination, harassment and victimisation, and to promote equality.

Protection against discrimination is also indirectly provided through legislation on personal data protection (the Data Protection Act 2018, the Human Rights Act, and also some soft law instrument). [see section on "Confidentiality and accessibility of personal data related to HIV positivity]

## Legislation that may provide basis for discrimination against PLHIV in healthcare settings

No legislation that could directly or indirectly discriminate against or provide basis for discrimination against PLHIV/AIDS in healthcare settings was reported.

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[197] The Human Rights Act 1998 c. 42 (UK). Available at: https://www.legislation.gov.uk/ukpga/1998/42/schedule/1

[198] The Equality Act 2010 c. 15 (UK). Available at: https://www.legislation.gov.uk/ukpga/2010/15/contents

## Means of reporting discrimination in healthcare settings (legal and other remedies)

When PLHIV come across discrimination in healthcare settings, several means of protection are available to them under UK law. These include:

- complaint to the healthcare provider/commissioner of the healthcare provider;
- complaint to the Parliamentary and Health Service Ombudsman;
- complaint to the Equality and Human Rights Commission;
- complaint to the Department of Health and Social Care (only applicable to complaints about services provided by the Department of Health and Social Care (i.e. not about the conduct ofhospitals, GPs or other NHS workers);
- civil lawsuit;

PLHIV in the UK are always encouraged to contact the NGOs working on discrimination and equality issues. [see the section on "Good practices in the national context"]

Complaint within the healthcare settings

Everyone has the right to make a complaint about any aspect of an NHS service. This is written into the NHS Constitution[199] and also in legislation – The Local Authority Social Services and National Health Service Complaints Regulations 2009[200].

Firstly, a patient should complain to the person or organisation providing the required healthcare service (e.g. the GP, dentist, hospital or pharmacist). Such complaint must be acknowledged within 3 working days and the provider should offer a meeting to discuss the problem. People are usually advised to attempt solving the problem informally rather than escalating to a formal complaint.

Secondly, a patient may choose to complain to the commissioner of the healthcare service in question – either NHS England (which commissions most primary care services, including GPs and dental services) or to the Clinical Commissioning Group (which oversees the commissioning of secondary care, including hospital care and some community services). Such complaints are to be submitted instead of the direct complaints to the provider as described in the previous paragraphs (i.e. a patient must select which complaint procedure he/she prefers; concurrent complaints may not be filed).

In addition, local authorities fund independent NHS complaints advocacy services which offer support to people that decide to lodge a complaint. These services are open to everybody and are free of charge. Each area also has a Healthwatch, which has a mission to feed local voices into the NHS leadership, but also carry out advocacy services including support with complaints.

People can also access the Patient Advice and Liaison Service, usually located in each hospital, which offers confidential advice, support and information on health-related matters and can support the complaints process.

Complaint to the Parliamentary and Health Service Ombudsman

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[199] Department of Health and Social Care. *The NHS Constitution for England*. Available at: https://www.gov.uk/government/publications/the-nhs-constitution-for-england

[200] The Local Authority Social Services and National Health Service Complaints Regulations 2009 No. 309 (UK). Available at: https://www.legislation.gov.uk/uksi/2009/309/contents/made

If a complaint made to a local healthcare provider or to the commissioner is not resolved, people can request an independent review from the Parliamentary and Health Service Ombudsman (hereinafter "PHSO"). A review will not take place if the PHSO believes that the complaint should be resolved locally (i.e. with the provider/commissioner), or if legal action is viable (regardless of whether it's underway). The PHSO can ask the relevant organisation to apologise to the complainant, can award financial compensation (although this would usually be lower than compensation awarded in court), and can ask the organisation to review and/or change procedures. If the complainant is not satisfied, the PHSO's decision can be appealed.

Complaint to the Equality and Human Rights Commission

The Equality and Human Right Commission (hereinafter "EHRC") promotes and upholds equality and human rights ideals and laws across England, Scotland, and Wales. The EHRC is a public body, and its budget has been slashed severely in recent years. It now only takes strategic cases. In Northern Ireland there is a separate Equality Commission (ECNI) and a Human Rights Commission (NIHRC).

Civil lawsuit

PLHIV who have been discriminated against by a healthcare provider can make a complaint or discrimination claim in the civil courts. Taking legal action via a court can be a stressful and expensive process. Since 2013, cuts to legal aid, which help people to pay for court action, have made it increasingly difficult for many people to challenge discrimination in the courts. It is often easier and more efficient to seek a resolution through the other remedies described above, however legal interventions are possible.

The court can order the healthcare provider to compensate the person who was discriminated against or grant an injunction. There are strict time limits for making a discrimination claim in the courts of six months less one day of the act which is the cause of the complaint. Although it is often encouraged that people take informal action before legal action to address discrimination, the time limits can make it difficult.

## Obligation of PLHIV to disclose their HIV+ status in healthcare settings

In the UK, there is no legal obligation for PLHIV that requires them to communicate their HIV+ status in healthcare settings.

## Confidentiality and accessibility of personal data related to HIV

In the UK, personal data protection is secured by several legislative documents. These protections are not HIV-specific. The Human Rights Act states that all individuals have a right to "*respect for private and family life*". The Data Protection Act 2018 controls how personal information is used and shared by organisations, businesses, or the government. The National Health Service Act 2006 clarifies that identifiable health-related data is confidential. In addition, General Medical Guidelines and National Health Service Guidelines on preserving patient confidentiality include specific guidance for "serious communicable diseases".[201,202,203]

Medical professionals are obliged, under common law, to keep personal information about a patient confidential, and are only entitled to share that information either: a) with the person's consent; or b) if the disclosure is in the "public interest".

Ad. a) A person is generally assumed to have implied their consent to their information being shared with another healthcare professional for their treatment or care, but they can refuse to have their information shared. Also, implied consent means that information can be shared by people who need to know the information to provide appropriate care, but not everyone (i.e. not to a person's family, care workers, etc.). In other words, any individual delivering care can access the person's health care record in order to provide appropriate healthcare. Individuals can withdraw consent for sharing of that information. If clinicians want to share information in instances unrelated to a person's treatment or care, explicit consent is required and may be withdrawn at any time.

Ad. b) Any disclosure of information in the public interest has to be shown to override the public interest of maintaining medical confidentiality.

There are some other (very uncommon) situations when the normal rules of confidentiality may not apply or be broken:

- if a court requests the information;
- in some cases, if the police request the information (attached to serious crimes such as terrorism and murder, not generally);
- if a doctor believes that someone with HIV is putting the life of another person in danger, the doctor may have the right to disclose information to the person in danger (this can only be as a last resort, and after telling the person with HIV that confidentiality will be broken).

Storing medical records

Health care information is stored in a Summary Care Record (hereinafter "SCR") held by the GP. Technically, this can be seen by all healthcare providers including pharmacists (to avoid drug interaction). Once a piece of information is added to the SCR it is virtually impossible to have it removed, even if it has been added in error. The most likely remedy is that it will also be recorded that the information is wrong.

Some HIV care is delivered in Genitourinary Medicine (hereinafter "GUM") clinics, but HIV care can also be delivered in, for example, an infectious diseases department in a hospital. GUM clinics hold records separately from hospital records with separate identifying numbers, but if you a person is seen for care in a department of a hospital then his/her HIV care record is part of the overall hospital record and therefore visible outside the HIV clinic. HIV care is "open access", meaning that anyone can go to any clinic. Therefore, a person could ensure that their sexual health

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[201] Department of Health and Social Care. *Confidentiality: NHS Code of Practice*. Available at: https://www.gov.uk/government/publications/confidentiality-nhs-code-of-practice

[202] General Medical Council. *Confidentiality: good practice in handling patient information*. Available at: https://www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/confidentiality

[203] General Medical Council. *Confidentiality: disclosing information about serious communicable diseases*. Available at: https://www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/confidentiality---disclosing-information-about-serious-communicable-diseases

information is not linked to their hospital record by going to a GUM clinic, but they'd have to know in advance the different systems and which providers are in which system, which is quite unlikely.

Pharmacists can read the SCR but not the full health record. Most pharmacists would be able to deduce a person's HIV status from their SCR, even if the HIV+ status is not recorded through withdrawal of consent.

For the last 5 years there has been a push in the healthcare settings to centralise medical records, and there are projects underway to replace SCR with shared care records, which would hold all healthcare information from all healthcare providers, rather than just the key information currently held in the SCR. These projects are locally specific.

Over the last decade there have also been nationally led efforts to centralise and standardise data collection and storage, including a recent attempt to secure anonymous data for research. The public are generally very wary of these efforts; and they have, as of yet, not been successful.

### Prohibitions and limitations on working in specific healthcare professions for PLHIV

Employment rights are guaranteed in the Equality Act 2010. Essentially, a person with a disability (which includes PLHIV) can be discriminated against in employment without a good reason.

Historically, there have been more restrictions but there has been considerable change over the last decade. Currently, there is no restriction on healthcare providers who are living with HIV, except for those who are conducting "Exposure Prone Procedures" (hereinafter "EPPs"). These are procedures, in which there is possibility for bleed back – commonly recognised as when the practitioner cannot see their own hands, e.g. in surgery.

Healthcare providers living with HIV can practice EPPs only if they are on ART, have a viral load of less than 200, have 3 monthly viral load monitoring checks, remain under the care of an HIV clinician, and register with the Occupational Health. Dentists are subject to the same rules as healthcare providers.

### Private insurance policies concerning PLHIV

The provision of private insurance policies for people living with HIV has historically been very limited in the UK. Although PLHIV are increasingly able to access affordable life and travel insurance, most insurance products related directly to someone's health remain inaccessible for them.

PLHIV remain ineligible for most income protection policies. The reason given by most insurers for this is that there is very little data on how HIV affects someone's attendance at work. Some PLHIV are able to access income protection insurance through their employer (group income protection) because it is usually not medically underwritten, meaning individual employees do not need to complete a medical questionnaire. HIV is usually included in these policies. People who are diagnosed with HIV after taking out a policy are sometimes covered for income loss as a result of their HIV, but it depends on the policy.

PLHIV are also not eligible for most critical illness policies as individuals. Some policies provide cover without a medical questionnaire; however, they usually state that the policy will not pay out if a pre-existing medical condition contributes to the occurrence of a critical illness. HIV itself is not a critical illness, but some policies will pay out for an HIV diagnosis depending on route of transmission. As with income protection policies, it is possible for PLHIV to secure cover through their employer.

### Common forms of discrimination in healthcare settings

All the common forms of discrimination against PLHIV indicated in the questionnaire (refusal-of-care, separation from other patients, provision of treatment at the end of office hours) were reported as occurring to some extent. Further problems were reported in the context of stigmatising behaviour (which, in some cases, does not reach the level to constitute discrimination by itself) and confidentiality breaches.

In 2017, Public Health England collected data from a random sample of people attending HIV clinics (4.422) in the survey "Positive Voices".[204] PLHIV were asked if they had been worried that they would be treated differently, had avoided seeking healthcare, had been treated differently from other patients, and if they felt they had been refused or delayed treatment.

81,8 % of the respondents had not avoided seeking healthcare, but 9,8 % had in the past year and 8,4 % had more than a year ago. Therefore, 2 in 10 people had avoided seeking healthcare when they need it, and 1 in 10 had avoided care in the past year.

81 % of the respondents said they had not been treated differently from other patients, but 7,6 % had in the past year, and 11,4 % had more than a year ago. This means 2 in 10 people had been treated differently from others because of their HIV status and 1 in 13 had been treated differently in the past year.

88,7 % of respondents did not feel that they had been refused or delayed medical care, but 5 % had in the past year and 6,3 % had more than a year ago. Therefore, 1 in 10 people had been refused or delayed access to care and for 1 in 20 this had happened in the past year.

Regarding the different healthcare settings, to some extent PLHIV may encounter discrimination in all the settings indicated in the questionnaire. The National AIDS Trust conducted a poll among PLHIV, accessed through the UK Community Advisory Board. The poll received 48 responses, meaning that it cannot be taken as representative of the entire community of PLHIV in the UK. However, certain recurring examples of discriminatory behaviour were described. This data may be used to at least illustrate what types of discriminatory practices PLHIV may come across in the various areas of healthcare.

In regard to secondary healthcare facilities, PLHIV most commonly reported being subjected to improper questions and comments, as well as practices of taking unnecessary "hygienic" precautions (e.g. double disinfection, double gloves, visors, etc.) or provision of treatment in special settings (i.e. providing ordinary procedures, that usually take place in clinic settings, in operating theatres). Similarly, PLHIV are often met with inappropriate and intrusive questions during GP visits. Although some of these practices by themselves may not always reach the severity to constitute discrimination, their cumulative impact may result in avoidance of seeking healthcare and worsening of a person's overall health condition. When respondents were asked about dental care, refusal-of-care or providing only the "absolutely necessary dental services" were frequently reported.

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[204] Public Health England. *Positive Voices: The National Survey of People Living with HIV*. Available at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/857922/PHE_positive_voices_report_2019.pdf

## Case studies

Several cases of discrimination against PLHIV in healthcare settings were dealt with over the past years by the UK equality bodies and other relevant institutions. The following cases best illustrate how the anti-discrimination instruments set out in the country function.

Discriminatory infection control policy (2020)

An individual living with HIV requiring elective surgery was moved to the end of the daily operating list because of his HIV status. The individual challenged the decision after his surgery by writing to the NHS Trust and asking for an explanation for why he was moved to the end of the daily operating lists. The NHS Trust replied to him saying that moving people living with HIV to end of daily operating lists was in accordance with their Standard Operational Policy for booking cases in theatres. The individual contacted National AIDS Trust for advice, and we wrote to the Chief Executive of the NHS Trust asking them to change the Standard Operational Policy for booking cases into theatres and set out that moving PLHIV to the end of the daily operating lists is not necessary and amounts to direct discrimination.

National AIDS Trust received a response from the NHS Trust which included an apology for the distress they had caused to the patient. The NHS Trust amended the Standard Operational Policy so that PLHIV would not be moved to the end of daily operating lists. The complaint letter was also shared with the surgery division so that staff could understand how and why the Standard Operational Policy had been amended.

Healthcare student removed from their course (2017)

A university student studying to be a mental health nurse contacted National AIDS Trust for support because they were threatened with expulsion (and ultimately removed) from their course for not disclosing their HIV+ status. There had also been several breaches of confidentiality between the university's occupational health service and the academic staff concerning the student's healthcare status.

The student's viral load was undetectable, and they were not performing or training to perform exposure prone procedures (hereinafter "EPPs"). It is well established in the UK that, under these circumstances, healthcare workers are not required to disclose their HIV+ status. National AIDS Trust supported the student to contest the decision to remove them from their course, and ultimately a satisfactory conclusion was reached.

National AIDS Trust also wrote to the UK Advisory Panel for Healthcare Workers Infected with Bloodborne Viruses, on the basis that ambiguity in its "Integrated Guidance on Health Clearance and the Management of HCWs Living with BBVs" led to the university's decision to discipline the student. The guidance was edited to ensure clarity regarding healthcare workers' right not to disclose their HIV+ status if they are not carrying out EPPs, and to make clear that it is inappropriate to ask healthcare workers specific questions about blood borne viruses in health screening questionnaires (if they wish to carry out EPPs they will be tested for BBVs).

Hair transplant procedure (2021)

George House Trust was approached by a man who was refused a hair transplant procedure at a clinic in Manchester. He was denied the treatment when he attended, with the clinician citing issues with insurance, COVID-19 precautions and the fact that he had not notified them of his HIV+ status before the procedure (on the form he said that he was 'undetectable' when it asked if he'd had a test for HIV).

During initial conversations, representatives made remarks about the "amount of blood involved" and how they only perform "riskier" procedures at their clinic in London as they have the necessary facilities. George House Trust have had ongoing discussions, notifying them of their responsibilities under the Equality Act and the need for universal precautions that should mean the procedure can be carried out at any of their clinics. They have also stated that the clinic in question is not directly managed by them and therefore they cannot force the clinician to perform the procedure. The issue has caused the service user much distress and discomfort. He had booked a hotel, told friends and family about the procedure, most of which do not know about his HIV+ status and taken time off work. The company have offered to do the procedure in London and to reimburse him for the cost of the hotel. They have also offered a payment of £500 as a goodwill gesture.

George House Trust have approached the Care Quality Commission and notified them of the incident.

## Good practices in the national context

Strategies introduced to tackle stigma and additional peer-support programmes

In 2019, an independent commission was launched to establish how to end HIV transmissions in England, supported and funded by National AIDS Trust, Terrence Higgins Trust and the Elton John AIDS Foundation.[205] Its recommendations incorporate considerations regarding stigma and health equity. These recommendations pertain to specific groups, e.g. trans people, or specific problems to be addressed, e.g. late diagnosis.

The Government has said that it will announce a new HIV Action Plan in England to incorporate the findings of the independent commission. In addition, an announcement is expected regarding the World AIDS Day and a new Sexual Health Strategy in 2022.

On the World AIDS Day 2020 the Scottish Government similarly announced a proposal for a plan to end HIV transmissions and stigma, but that appears to have been delayed due to COVID-19.

Some secondary care providers are developing anti-stigma policies and working on monitoring the level of HIV awareness and knowledge. HIV clinics have also often embedded peer support. Some Primary Care Networks (groups of GP practices), especially those in higher prevalence areas, have so called "HIV champions".

Healthy London Partnerships (a collaboration of London local government and health bodies) has proposals to tackle HIV-related stigma in London, including in healthcare settings.[206] Fast-track Cities London, in collaboration with Healthy London Partnership, has also been doing a wider piece of work on integrated care which includes a considerable stigma component and is specifically working on tackling HIV-related stigma in London, including in healthcare settings.[207] Work on this front has been delayed by COVID-19.

Support provided by local NGOs

PLHIV in the UK are always encouraged to contact the NGOs working on discrimination and equality issues. These include the British Institute for Human Rights (BIHR) and Equally Ours (formerly, the Equality and Diversity Forum). National Voices is an umbrella organisation that aims to ensure patient voice is represented in all decisions made about people living with health conditions and impairments.

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[205] HIV Commission. *The HIV Commission's Final Report and Recommendations: Executive Summary*. Available at: https://www.hivcommission.org.uk/wp-content/uploads/2020/12/HIV-Commission-Executive-Summary_online_final_pages.pdf

[206] Healthy London Partnership. *Fast-Track Cities HIV anti-stigma work*. Available at: https://www.healthylondon.org/our-work/fast-track-cities-initiative/hiv-related-stigma-work-in-london/

[207] Fast-Track Cities London. *Draft proposals to tackle HIV-related stigma in London – have your say*. Available at: https://www.healthylondon.org/wp-content/uploads/2019/12/Fast-Track-Cities-London-stigma-proposal-engagement-document-for-feedback.pdf

Specifically in relation to HIV, National AIDS Trust works with HIV support services and others working with PLHIV to challenge discrimination experienced by their clients. This includes discrimination in healthcare settings, as well as in employment and accessing private services.

The information and support provided through this work is informed by advice from specialist civil rights and judicial rights solicitors Deighton Pierce Glynn. As part of this work, National AIDS Trust has been contacted by HIV support service staff, social workers and clinicians for advice relating to potential incidences of discrimination based on someone's HIV+ status in healthcare settings.

In addition to providing advice, the NGOs are also creating resources to help those supporting PLHIV challenge discrimination in healthcare settings. These include fact sheets, guidance and template letters. The NGOs also provide annual training to the HIV sector, in conjunction with Deighton Pierce Glynn, on using the law to challenge discrimination experienced by their clients. In 2021, the organised session focuses on challenging discrimination in healthcare settings.

Age+ project

An HIV specialist support service, George House Trust, has recently launched a project called "Age+" that provides a range of activities and services for people aged 55 and over. As part of the project, they are currently developing a kite marked training programme for care providers in Greater Manchester. This has been done in recognition of the fact that many older people are anxious at the prospect of entering care/nursing homes due to the risk of discrimination and potential prejudice. The training is being developed and will be delivered by a team of volunteers and PLHIV. The project is funded by George House Trust and Viiv Healthcare.

GP training programme in greater Manchester

George House Trust has been working with GPs across Greater Manchester as part of their "Positively Speaking" programme. The aim is to increase knowledge and understanding amongst GPs and staff in primary care. The sessions include a Q&A with a clinician and a talk from one of our Positive Speakers (PLHIV).

## Issues and bad practices in the national context

In the UK, issues and bad practices in the national context were reported to mainly consist of the behaviour described in the sections on discrimination and confidentiality. These issues are further supported by the lack of appropriate knowledge about HIV/AIDS among doctors, nurses and particularly GPs who are not aware of the up-to-date knowledge regarding HIV transmission risks, development in treatment, and the U=U doctrine. [see sections on "Confidentiality and accessibility of personal data related to HIV" and "Common forms of discrimination"]

## COVID-19 impact on PLHIV

Access to HIV care[208]

The Covid-19 pandemic had an impact on the provision of HIV-related services in 2020. Fewer people accessed HIV care. 93.780 people diagnosed as HIV+ were expected to attend HIV services in 2020; however, only

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[208] UK Health Security Agency. *HIV testing, new HIV diagnoses, outcomes and quality of care for people accessing HIV services: 2021 report*. Available at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1037215/hiv-2021-report.pdf

88.800 people did. This means that approximately 5.000 people with diagnosed HIV infection did not seek HIV treatment. In comparison, in 2019, this number was reported to be significantly lower at 3.600.

Delivery of HIV care also changed with telephone consultations increasing from 7.910 consultations in 2019 to 59.280 consultations in 2020.

Inclusion of PLHIV in priority vaccination groups[209]

COVID-19 vaccination in the UK follows vaccination scheme in which 10 vaccination groups have been established based on "vulnerability".

PLHIV were included in priority group 6 "Adults aged 16 to 65 years in an at-risk group". PLHIV with a low CD4 count were included in priority group 4 "All those 70 years of age and over and clinically extremely vulnerable individuals"; for these individuals, a shielding programme was introduced in England.

Shielding of PLHIV with a low CD4 count

The centrally-administered list of "clinically extremely vulnerable" people, who were advised to shield from COVID-19 exposure, was managed through general practice records. General practice records in the UK do not routinely hold data on the severity of HIV infection, e.g. CD4 counts.

British HIV Association (BHIVA) advice was that HIV infection only constituted grounds for shielding if the patient had a CD4 count below 50 cells/mm$^3$, or if the patient had experienced an opportunistic infection in the past 6 months. This specification was not built into the central system for communicating with people who were clinically extremely vulnerable.

As a result, shielding instructions for PLHIV often went out unnecessarily, or not at all. National AIDS Trust and other HIV charities received communications from many people living with HIV who were asked to shield in error (e.g. because they were incorrectly reported to be 'immunosuppressed' in GP data, or latterly because the 2021 QCovid algorithm overstated the vulnerability of people living with HIV to serious illness from COVID-19 without accounting for CD4 count). HIV clinicians were in the end able to remove patients from this centrally-managed list, but this option was not centrally communicated.

PLHIV who indeed needed to shield on these grounds reported concerns around sharing their HIV+ status with their employer. National AIDS Trust produced guidance on how to secure certification of shielding status without disclosing one's HIV+ status.

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[209] Public Health England. *COVID-19 vaccination first phase priority groups*. Available at: https://www.gov.uk/government/publications/covid-19-vaccination-care-home-and-healthcare-settings-posters/covid-19-vaccination-first-phase-priority-groups