# Increasing and normalising HIV testing across the UK

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# Definitions

**Online testing** - Ordering your test online to be delivered at home.

**HIV self-testing** - A test that requires a minuscule amount of blood to put into a test, similar to a pregnancy test. The person will have a short 15 minute wait until they know their own status, there and then.

**HIV self-sampling** - A test that requires enough blood to fill the collection tube which is approximately 600ul. Then the blood is sent in the post back to a laboratory where the test is performed. The person will then be notified of the result.

**HIV** - HIV (human immunodeficiency virus) is a virus that attacks the body's immune system. If HIV is not treated, it can lead to AIDS (acquired immunodeficiency syndrome). There is currently no effective cure. Once people get HIV, they have it for life. But with proper medical care, HIV can be controlled.

**AIDS** - AIDS (acquired immune deficiency syndrome) is the name used to describe a number of potentially life-threatening infections and illnesses that happen when your immune system has been severely damaged by the HIV virus. While AIDS cannot be transmitted from 1 person to another, the HIV virus can.

**PrEP** - PrEP (pre-exposure prophylaxis) is a pill people can take regularly to prevent them getting HIV from sex or injection drug use. When taken as prescribed, PrEP is highly effective for preventing HIV.

**PEP** - PEP (sometimes called PEPSE) is a combination of HIV drugs that can stop the virus taking hold. It can be used after the event if you believe you may be at risk of HIV transmission.

**BAME** - Black, Asian and Minority Ethnic (BAME) communities

**HIV-1** & **HIV-2** - HIV-1 and HIV-2 are two distinct viruses. Worldwide, the predominant virus is HIV-1. HIV-1 accounts for around 95% of all infections worldwide. HIV-2 is estimated to be more than 55% genetically distinct from HIV-1.

**U=U** - Undetectable = Untransmittable' (U=U) is a campaign explaining how the sexual transmission of HIV can be stopped. When a person is living with HIV and is on effective treatment, it lowers the level of HIV (the viral load) in the blood. When the levels are extremely low (below 200 copies/ml of blood measured) it is referred to as an undetectable viral load. This is also medically known as virally suppressed. At this stage, HIV cannot be passed on sexually.

# List of Abbreviations

| | |
|---|---|
| **APPG** | All Party Parliamentary Group |
| **ART** | Antiretroviral therapy |
| **BAME** | Black Asian and Minority Ethnic |
| **BHIVA** | British HIV Association |
| **BASHH** | British Association for Sexual Health and HIV |
| **CHIVA** | Children's HIV Association |
| **DHSE** | Department for Health and Social Care |
| **DWP** | Department for Work and Pensions |
| **EJAF** | Elton John AIDS Foundation |
| **HPE** | HIV Prevention England |
| **ICS** | Integrated Care System |
| **LGBT** | Lesbian Gay Bisexual and Transgender |
| **MSM** | Men who have sex with men |
| **NAT** | National AIDS Trust |
| **NHIVTW** | National HIV Testing Week |
| **PHE** | Public Health England |
| **PHW** | Public Health Wales |
| **QoL** | Quality of Life |
| **SHS** | Sexual Health Service |
| **SIBS** | Social Impact Bond |
| **STI** | Sexually Transmitted Infection |
| **THT** | Terrence Higgins Trust |

# Foreword: Chair

The push to end HIV transmissions by 2030 across the UK has been remarkable. The UK, Scottish and Welsh governments have all committed to meeting this target by building on the work of people living with HIV, campaigners, HIV charities, expert healthcare professionals and the Fast-Track Cities initiative.

Despite the progress made in the four nations, they are not yet on track to meet the 2030 goal. This report builds on the work of the The English HIV Commission by listening to organisations across the four nations to see what HIV testing could look like to help meet this ambition. COVID-19, another global health challenge, has emerged and highlighted the challenges we face in addressing health inequalities and new ways of working to meet those challenges. The impact from COVID-19 on the public health system could be long-lasting, but we must not allow it to steer us off track in meeting this target.

The message from the HIV sector and Public Health professionals is to 'test, test, test'. Late diagnosis remains high. There are still far too many people living with undiagnosed HIV who are not going to be reached through existing testing strategies alone. To find the estimated 6,500 undiagnosed people living with HIV in the UK, HIV testing must be normalised throughout the health service and beyond. Everyone should know their HIV status, and there needs to be equitable and easy access for everyone to this knowledge, and the resulting effective treatment to ensure they can live a full and healthy life with undetectable HIV.

If we get this right, the four nations will not just have closed a chapter domestically on a four decade long pandemic but be a global leader in the fight against HIV. If all the governments embrace the recommendations in this report, we are on the way to ensuring that we end new transmissions of HIV in the UK.

I want to thank all the organisations who have taken the time to submit evidence and helped shape this inquiry. I am immensely grateful for your contribution. The report reflects the commitment all of you have to the fight against HIV and to helping those living with HIV. I would also like to acknowledge that this report builds on the HIV Commissions report and our recommendations are in line with theirs.

Publication of these recommendations is only the beginning; we now must see a comprehensive HIV Action Plan in each of the four nations. The HIV community will, I am sure, watch the four governments' responses closely to this report and hold decision makers to account to ensure implementation is prompt and comprehensive.

The message to the four governments is clear, TEST, TEST, TEST.

**Stephen Doughty MP**
*Chair of the All Party Parliamentary Group on HIV and AIDS*

# Foreword: Dr Laura Waters (BHIVA)

HIV care in the UK is excellent. The proportion and number of people living with undiagnosed HIV has declined year on year, and the majority of people with diagnosed HIV are undetectable on treatment. Effective treatment and combination HIV prevention, including pre-exposure prophylaxis, have resulted in a marked decline in new HIV diagnoses annually. However, despite the fact we have access to all the tools we need to eliminate new HIV transmissions, we will not meet the HIV Commission targets to do so by 2030, nor the Government's commitment to reduce new diagnoses by 80% by 2025, unless we improve testing.

We know that undiagnosed HIV is a major contributor to onward transmission and driver of late presentation, which in turn significantly increases the risk of death in the first year after diagnosis. We know that HIV testing is reliable, cost-effective, and highly acceptable to patients across a range of services and settings. We have national guidelines for HIV testing from specialist societies and from NICE. Yet 1 in 12 people with HIV does not know their status, guidelines are not implemented universally and people diagnosed late will often have had previous contacts with health services where the opportunity to test for HIV was missed. This must change. If people attending sexual health services can leave a clinic without the offer of an HIV test it is hard to hold non-specialist settings to the same standards. Failure to offer an HIV test risks not only a missed HIV diagnosis; we miss the opportunity to fully understand the reasons to decline a test and to address these with appropriate interventions; we miss the opportunity to discuss HIV prevention tools.

Many people at risk of HIV or living with undiagnosed HIV will not attend sexual health services, so we must embed routine HIV testing within all healthcare settings. It is not acceptable for anyone with an HIV indicator condition to not be offered an HIV test, but until all speciality guidelines are updated to reflect this, HIV testing will not be normalised. Fragmented commissioning has allowed debates about funding and responsibilities to curtail HIV testing rollout – resolving this is a priority. And even if guidelines are aligned, and adequate resources are allocated, all staff, in all settings, must feel confident to offer HIV testing for it to become routine.

The opportunity to eliminate new cases of a long-term condition is rare, yet we have the tools to do just that, now! We must grasp that opportunity and create a culture where failure to follow guidelines is considered wrong and HIV testing considered routine.

**Dr Laura Waters**
*Chair, British HIV Association*

# Foreword: Parminder Sekhon (NAZ)

We at NAZ welcome this report and its recommendations. We regard it as a real lever for change.

The earlier someone is diagnosed with HIV, the sooner they can begin treatment. They get to stay well and the transmission on to others can be prevented. Yet four decades on, shame, stigma and fear are still driving late diagnosis of HIV in a way that is unacceptable and entirely preventable.

There have been notable improvements in the identification and treatment of HIV but they have not been experienced equally in society. It is more than a disparity, an unequal outcome, a familiar graph in an annual report. Let us be clear about what we are talking about: people of black ethnicities and people from deprived backgrounds experience vastly different health outcomes compared to the wider population. This needs to be prioritised.

One vital way to address these differences in outcomes lies in the way testing reaches our communities. We still need to ask some uncomfortable questions of why there are still so many testing opportunities that are missed within statutory settings. We want to ensure that the offer of HIV testing to all populations becomes routine across the four nations of the UK.

But offering testing and uptake of testing are two quite different things. We need to deepen our understanding of the structural barriers that make engagement harder for certain groups. We need to acknowledge the impact of these barriers that disadvantage communities and put them at elevated risk of HIV. And this learning needs to be informed by the Covid experience. Problematising communities that have been under-served and structurally marginalised for decades by both legislation and resource adds further injury to the accumulative disadvantage they have already faced. We have an opportunity to re double our efforts to reach those that need our support the most by understanding what motivates testing anxiety and our collective role in creating a more inclusive environment.

We welcome how the report acknowledges the 2016 BHIVA recommendation and reframes late diagnosis as the serious incidents that they are.

Offering a test alone will not end this epidemic. Our testing offer is only as good as the systems around it. We are privileged to have world-class centres of treatment and miraculous prevention technologies and the expertise to eradicate HIV. We have an excellent health care system staffed by dedicated professionals and supported by an irrepressible and specialist third sector.

The infrastructure across this landscape needs to change. Data collections must be improved so we can target our resources to those that need them most. If some of the steps in our pathways of care are broken or inconsistent, then our systems are not working for the people we serve. We need to acknowledge this reality and pledge our collective commitment to fix what is required.

These issues are arguably even more marked outside of London in both rural and urban spaces and we need to invest testing and support infrastructure in other parts of the country where deprivation and resource is compromising testing engagement and outcomes.

This report contains all the ingredients required to achieve zero HIV transmissions by 2030. It serves as a sobering reminder of the work that remains to be done if we are all to cross the finishing line together.

**Parminder Sekhon**
*Chief Executive Officer, NAZ*

# Acknowledgements

Thank you to all of the 36 organisations and individuals who have worked with us throughout the course of the inquiry. This report was compiled by **Mark Lewis**, Senior Policy Advisor to the APPG on HIV and AIDS. If you would like further copies please contact **mark.lewis@parliament.uk**

We would like to thank **National AIDS Trust**, **Elton John AIDS Foundation**, **Terrence Higgins Trust**, **The Love Tank**, **NAZ**, **Alex Sparrowhawk** and **Lisa Power** for their guidance during this inquiry.

# Methodology

The APPG put out a call for written evidence on 10th February 2021 and we received 36 submissions. This inquiry deals with HIV testing across the UK.

While the report recognises that different groups of people have different needs – for instance, diverse BAME groups, heterosexual, gay and bisexual men, women, trans, non-binary, gender diverse people, older people, children and young people, people who use drugs and formerly used drugs, people from diverse religious backgrounds, refugees and asylum seekers, and the many people with HIV who have experienced trauma - we use examples which we encountered from our research which do not necessarily reflect the full spectrum of communities within the broader group of people who need to be targeted for HIV testing. The reflections and recommendations however apply to all people at risk of HIV.

# Executive Summary

Devolution has brought us four different ways of providing sexual health and HIV services in the UK. However, this should not stop the four nations working together in ensuring we beat HIV, a disease that does not recognise borders.

Wales became the first country to commit to ending new transmissions of HIV by 2030, followed by England and Scotland. The Northern Ireland Executive have not committed to the target but they have acknowledged it.

Despite these commitments and the progress made there is still so much to do. After hearing from organisations across the UK, the publication of the HIV Commission report and the broadcasting of It's A Sin on Channel 4, we hope that all four Governments co-ordinate constructively towards this common endeavour.

In the UK there were 4139 new infections recorded in 2019. If the four Governments adopt these recommendations into their HIV action plans, this will enable us to meet that crucial but achievable target of ending new transmissions of HIV by 2030.

**Our key recommendation is to ensure opt-out testing when patients register for a GP, present at A&E or when the NHS takes blood samples across all kinds of healthcare settings.** This is an opportunity we cannot miss to diagnose every case of HIV, stop preventable transmissions and bring back into treatment those who have been diagnosed lost to the system.

We have seen in maternity units how effective this approach to testing is. Midwifery services have almost completely eliminated vertical transmission to children. HIV testing is mainstream in maternity units, where midwives handle the associated issues with care and consideration and, critically, without judgement. Every health and social care setting must follow suit.

A recent Public Health England report showed that overall coverage of HIV testing in specialist Sexual Health Services (SHS) was 65%. There is clearly room for improvement. Of the 549,849 people not tested for HIV, 46% were not offered a test and the remainder declined testing, or those who knew their status already. heterosexual women were more likely than heterosexual men to decline a test (25% vs 13%). Few Gay Black Men declined testing (4%), in contrast to 20% of Black African heterosexual women and 9% of Black African heterosexual men. High rates of declined tests, in addition to the 15% of Black African heterosexual women who were not offered an HIV test, resulted in over a third of Black African heterosexual women attendees not being tested at specialist SHS[1].

1 https://www.gov.uk/government/statistics/hiv-annual-data-tables

Ensuring opt-out and more accessible testing will not only stop late diagnosis but identify those lost to the system and those who are living with HIV who don't know their status. Ending late diagnosis is good for the health of people living with HIV and prevents new transmissions while saving money by preventing declining health outcomes and the costs associated with long term care.

COVID-19 has exposed and exacerbated how structural inequalities linked to issues of poverty, race and immigration have implications for health. It has also changed the HIV landscape significantly. People's sex lives have changed, and there has been an increased reluctance to and difficulty in accessing services. As a result, there is evidence of less face to face testing, and increased reliance on online testing. Our recommendations consider this challenge and how we can better react to change going forward.

It is crucial that HIV and AIDS remains firmly on the agenda of the four Governments both domestically and internationally – who must be held to their promise to reach zero new infections by 2030.

# Recommendations

## Area 1: Testing in sexual health services:

1. Sexual health services should move to an opt-out system of HIV testing and no one should leave a clinic without being offered an HIV test and being signposted to at-home HIV testing services where these are available.
2. All clinicians and frontline staff across health and social care should receive regular training so they are confident in having discussions about HIV, HIV prevention and HIV testing. This training should also focus on the barriers to HIV testing including stigma, racism, transphobia and wider discrimination.
3. The reasons why people decline an HIV test need to be better understood and this data should be captured and made available throughout the UK.
4. There should be access to at-home HIV testing services across the UK, with a particular focus on rural areas which are often most underserved by sexual health clinics.
5. A National Campaign to educate the population on the benefits of PrEP needs to be formed and implemented.

## Area 2: Testing in Primary Care and Accident and Emergency Departments:

1. Opt-out rather than opt-in HIV testing must become routine across healthcare settings, starting with areas of high prevalence.
2. Any HIV Action Plan adopted by any of the four governments must include the development of a strategy for recruitment, training, and retention of the HIV workforce, in clinical settings, local government and the voluntary sector.
3. Training about HIV, HIV prevention and HIV testing including barriers to HIV testing, stigma, racism, transphobia and wider discrimination should be made mandatory across the NHS and social care workforce.
4. Funding should be made available to implement a programme of coordinated campaigns in the UK across the decade, to enable residents in the UK to know how to find out their HIV status and increase their awareness of combination HIV prevention.
5. All late HIV diagnoses must be investigated as a serious incident by the National Institute for Health Protection, working with BHIVA, NHS Trusts, Health Boards, local authorities, and Clinical Commissioning Groups.

## Area 3: People presenting with HIV indicator condition should receive HIV tests:

1. All relevant medical Royal Colleges, Faculties and other professional organisations to review and update their guidance on recommending HIV tests for patients with indicator conditions.
2. NICE should review relevant indicator condition guidance to include recommendations around HIV testing in line with existing NICE HIV guidance.

3. The four Departments of Health should provide additional clarity over commissioning responsibilities for indicator conditions and ensure resources are provided to enable testing and the training needed to deliver it.
4. Local commissioners across the UK to ensure they are providing resources to enable HIV indicator condition testing as part of the commissioning arrangements.
5. All four nations should review their policies and ensure clinical departments are consistently testing for HIV in patients presenting with indicator conditions.
6. GP practices, practice care networks and federations should ensure they identify patients with indicator conditions proactively, using GP records and data, and offer HIV tests to these patients.
7. The four nations should recognise unmet need in the sexual health sector and provide a radical uplift in public health funding, particularly investing in local sexual and reproductive health services.
8. As more people living with HIV access non-specialised healthcare, training on HIV and sexual health should be mandatory for the entire health care workforce to address HIV stigma and improve knowledge of indicator conditions.
9. The four Departments of Health and Social Care and their agencies should collaborate more closely on the commissioning of sexual health and HIV services; and ensure greater integration of services to ensure seamless, patient-centred care.

## Area 4: Ideas for implementation going forward:

1. The UK Government working with the Welsh and Scottish Parliaments and the Northern Ireland Executive must review and assess the impact of current policies and legislation which act as a barrier to HIV elimination progress or where performance improvement is needed.
2. Clarity is needed around where funding responsibilities for HIV mental health and peer support services sit.
3. The four Governments should conduct a review to end digital poverty and exclusion.
4. Existing HIV testing guidance should be fully implemented including routine testing for those with common indicator conditions
5. Funding is required to appropriately resource the provision of HIV tests and the laboratory capacity to process them in a timely way.

## Area 5: Engaging under-represented groups in HIV testing.

1. Services delivering HIV self-testing to under-represented groups in the UK should be implemented to support these groups.
2. More tailored and targeted HIV interventions are needed to reach out to these under-represented groups.
3. The four Departments for Health and Social Care along with the HIV voluntary sector need to engage with community-based organisations and faith groups that work within target communities to enable the facilitation of community testing.

4. Interventions need to take account of the different identities that exist who need to be reached and be tailored and targeted to those specific groups.
5. More research is needed to provide data on marginalised communities so as to better understand their needs. Disaggregated data and research would inform targeting, identify gaps and address barriers to testing more effectively.
6. Anti-stigma campaigns and interventions to increase understanding, dispel myths and change attitudes towards HIV and HIV testing are needed to engage with the under-represented groups.
7. Training and continuous professional development should be implemented for those working in a clinical setting to increase the knowledge and awareness of the healthcare workforce on HIV.
8. An audit of public sector data sources should be conducted to establish where there are gaps in data collection and how data collection methods can be streamlined. This needs to be consistent across local authorities, Public Health Agencies and the NHS. Data needs to be disaggregated for BAME ethnicities in order to understand the needs of each group and where to target services.

## Area 6: The future of online, home and community testing.

1. The flexibility and granularity of data collection systems must be maximised to meet the changing face of HIV and tackle inequity, including reporting on all communities.
2. At a local level, existing processes of transferring patient information between sexual health clinics, secondary care and primary care should be examined to ensure best practice.
3. Secondary care clinicians must have the resources they need to signpost and communicate with colleagues in other sectors effectively.
4. Health and care systems must adopt innovations in a timely fashion, considering equitable access to innovation at every stage of planning and implementation. This includes telehealth, online testing and new biomedical technologies.
5. The HIV Action Plans adopted by all four nations should include funding for opt-out HIV testing across the NHS, free at-home HIV testing available year round, a step change in health promotion programmes, action to reduce late HIV diagnosis and a new anti-HIV stigma campaign.
6. There should be a coordinated HIV Testing Week across the UK, aligned with European HIV Testing Week.
7. Digital infrastructures should be scaled up for people on low incomes and living in poverty, creating easier access to HIV testing and the wider healthcare system.
8. Programmes, Campaigns and Services need to be co-designed with the communities they are trying to reach, so that the different cultures, languages, and faiths are accounted for.

## England Specific

1. NHS England and the Department of Health and Social Care should provide additional clarity over commissioning responsibilities for indicator conditions to ensure resources are provided to enable testing and the training needed to deliver it.
2. The Treasury and Department of Health and Social Care must recognise unmet need in the sexual health sector and provide a commensurate uplift in public health funding, particularly investments in local sexual and reproductive health services.

## Wales Specific:

1. The Welsh Government should follow up on their radical pledge to establish an HIV Action Plan to reach zero new transmissions by 2030.
2. There should be continued funding of the national HIV and STI postal testing scheme and governmental support for a Welsh National HIV Testing Week within a UK-wide initiative.
3. Public Health Wales should establish a single national HIV surveillance and data system.
4. A national information campaign on the benefits of HIV testing and treatment advances should be produced.

## Scotland Specific:

1. The Scottish Government should provide a wide and diverse approach to HIV testing.
2. The Scottish Government should ensure a clear consensus on HIV testing guidelines.
3. The Scottish Government should renew the HIV Action Plan before the end of 2021.

## Northern Ireland Specific:

1. The Northern Ireland Executive should develop an HIV action plan for Northern Ireland and commit to the 2030 taregt.
2. The Northern Ireland Executive should adopt a universal opt-out testing procedure for Northern Ireland.
3. The Northern Ireland Executive should explore the possibility of cross-border agreements for sexual health support services and testing with the Republic of Ireland.

# Introduction

Early diagnosis and rapid initiation of antiretroviral therapy is a key strategy in the control of the global HIV/AIDS epidemics. Earlier access to testing for HIV and subsequent uptake of antiretroviral therapy can improve health outcomes of people living with HIV, potentially eliminating the risk of HIV transmission and reducing HIV rates.

While the first AIDS cases were reported in 1981, HIV wasn't discovered until 1984 and ELISA, the first test for HIV, did not become available until 1985. This was a blood test that looked for HIV antibodies, which meant that a person had to have been already infected with HIV for three to twelve weeks — the time it takes to develop HIV antibodies — to test positive. That test was also not as accurate as those that would follow, offering a significant number of false positive results. At the time, it was generally used to test the blood supply, not individuals.

In 1987 a much more accurate but more difficult to perform test, known as the Western Blot, became available. Though the test would seem as simple as blood being drawn from a patient's perspective, that blood would still first be sent for an ELISA test, and if it came back positive, the Western Blot test would be used to confirm that result. This meant that the wait time for results was a nerve-wracking two weeks. Like ELISA, the Western Blot also depended on antibodies, rendering tests within the first few months of infection potentially inaccurate.

In the late 1980s came second and third generation HIV tests. These tests also looked for antibodies but were more reliable and tested not only for HIV-1 (common worldwide) but also for HIV-2 (more common in West Africa). These tests could also register antibodies sooner, within approximately four to six weeks of infection.

In the 1990s and 2000s, fourth generation HIV tests arrived, which tested for not only HIV antibodies but also for HIV antigens, a part of the virus itself. This allowed a positive result in as little as two weeks after infection. Today's fifth generation tests can distinguish between HIV-1 and HIV-2 and also differentiate between antibodies and antigens, which provides valuable information about the progress of the infection.

In addition to being able to detect HIV sooner after infection, the waiting period between testing and results has been drastically reduced. The process can begin with a finger prick or blood draw. Fortunately, there is no longer a two-week waiting period for results. Nowadays, rapid testing — by which results can be obtained in 10-20 minutes — can be used with all but the finger prick method. Rapid test by finger prick is, however, currently the most widely used method around the UK. Though a positive result will require confirmation by a more conventional method (which takes longer), a negative test generally means no further screening is necessary until someone's next regular test.

Research is making it ever clearer that HIV is most commonly spread by people who don't know their status, which means getting tested is one of the most important ways you can help stop HIV from spreading.

Free and confidential HIV testing is available for everyone, regardless of immigration or residency status, through open access sexual health services.

Over the last decade we have seen an increase in HIV testing rates in the UK. There are many barriers that undermine the uptake of HIV testing at both the individual (e.g. fear, stigma, perceptions of risk, embarrassment in talking with health professionals) and health service level (e.g., testing location, wait time for results, cost).

This report will look at the current provisions for HIV testing, what other areas testing should be made available and why some people are not being tested when they should be. It will also look at the barriers faced by the underserved communities (BAME, Trans, Women, migrants) and where do we go next to ensure better access to HIV testing.

Alongside condoms, Pre-Exposure Prophylaxis and U=U, HIV testing is our other major tool in fighting HIV. Making HIV testing more accessible and normalised will be the only way we end new transmissions of HIV by 2030, so we can get more people to know their status and onto treatment.

# Report Format

**Area 1:** **Testing in sexual health services:**

**Area 2:** **Testing in Primary Care and Accident and Emergency Departments:**

**Area 3:** **People presenting with HIV indicator condition should receive HIV tests:**

**Area 4:** **Ideas for implementation going forward:**

**Area 5:** **Engaging under-represented groups in HIV testing:**

**Area 6:** **The future of online, home and community testing:**

# Area 1:
# Testing in sexual health services:

***"HIV has changed a lot since the 1980s, and it affects women and heterosexuals equally as gay men."***
***Ian Green – CEO Terrence Higgins Trust[2]***

Sexual health clinics have been at the forefront of diagnosing HIV for almost four decades. Testing is the only way to find out if an individual has HIV and, with the advent of effective treatment which stops the virus being passed on, is now central to prevention efforts to eliminate AIDS-related deaths and to reduce HIV transmission. Testing technology has also developed rapidly, reducing waiting time for results and increasing their efficacy.

With different healthcare structures in each of the four nations, sexual health services are still the cornerstone of HIV prevention and play a crucial role in diagnosing the approximately 6,700 people living with HIV across the UK who do not know their status. Appendix 1 shows how each UK country delivers sexual health services.

There remain barriers to obtaining an HIV test, as stated by BASHH, Fast Track Cardiff & Vale, George House Trust, Waverly Care and others that need to be addressed in the provision of sexual health services. These are:

## Structural:

The location and visibility of specialist sexual health and HIV services along with opening hours, lack of signposting, capacity of the centre and waiting times were suggested by a number of organisations as a deterrent to accessing a sexual health service for HIV testing.

## Cultural:

BHIVA and BASSH suggest that due to the increasingly diverse communities in the UK there are increasing cultural and language barriers preventing people from accessing HIV testing. There are also communication barriers in letting people know that sexual healthcare is free at the point of access regardless of residency status. This in turn leads to the lack of a targeted approach in making care accessible to some higher risk populations.
(Please see section 5 for further details).

2 https://www.independent.co.uk/life-style/health-and-families/hiv-testing-week-aids-uk-b1796272.html

## Case Study:

### An example of stigma and discrimination: British Pakistani Gay Man, 20

***He came out to his parents 8 months ago and was forced to leave Bradford. He then came to London hoping to find a supportive environment and be able to express his identity. He did not have a job and began to couch surf, and this soon escalated into sex work and chems. He felt this was the only way he could secure a roof over his head. A client with whom he had sex told him he had been diagnosed with HIV. He was extremely anxious and worried; he had not been tested since he had come to London and said he did not feel comfortable to go to a mainstream service for fear of judgment. The NAZ Project offered him a same day test and referred him to a service for sex workers and to a housing association. He now has a place of his own, accessing welfare benefits; he is no longer engaged in selling sex and self-reports to be in a better place[3].***

## Geographical:

The majority of UK sexual health care occurs in primary care. Access to specialist sexual health services is variable across the geography, with specialist services concentrated in areas of high-density population and so may not reflect local need elsewhere.

In Wales there is a clear lack of dedicated services in mid-Wales and, given poor public transport, many people have long journeys even in the rest of Wales, making face to face services difficult to access. The map attached in Appendix One shows the location of sexual health clinics in Wales and the areas within 15 minutes travel time to them.

In Scotland there is similarly no equality of opportunity to access testing based on location. As explained by HIV Scotland and Waverly Care, access to services within the 'city' health boards is more convenient for people living in large population centres. However, when it comes to rural communities, as in Wales individuals would often need to travel long distances to access services.

Positive Life Northern Ireland stated that due to the scale back in services in Northern Ireland, sexual health and HIV services are only available through three genitourinary medicine (GUM) clinics/sexual health clinics located in Belfast (the Belfast Trust), Downpatrick (the South Eastern Trust), and Derry/Londonderry (the Western Trust).

Although sexual health services in England tested more than 1 million people for HIV in 2019[4] there are also geographical inequalities in sexual healthcare across England, with inequity between urban and rural settings, leading to variable access for patients.

## Informational:

What we know about testing, treating and preventing HIV has changed substantially in the past decade. We know that HIV treatment will keep someone alive while preventing onward transmission; that treatment is available to prevent acquiring HIV in the first place; and that testing can be simpler, faster and more convenient than ever before.

The recent rises in HIV testing for example following media coverage of the television series 'It's A Sin' and before that Prince Harry publicly taking a test and of rugby star Gareth Thomas' HIV status show that appropriate messaging and visible role models can encourage testing. We saw the impact of 'It's A Sin' during National HIV Testing Week in England this year, when on a single day more people checked their HIV status than during the whole of 2019's Testing Week[5]. Public Health Wales stated that before It's A Sin aired around 57.7% of the 6,700 STI kits ordered in January included a request for an HIV blood test, which rose to 62.3% after the first episode was broadcast.

3 NAZ submission
4 (PHE data https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_ data/file/959330/hpr2020_hiv19.pdf)
5 Joint Submission by THT, NAT and EJAF

During National HIV Testing Week, PHE makes it possible for people from across England to order a test, but the promotion of testing and universal access to online testing is restricted overall, and capacity is limited to the number of tests available.

In Wales little has been done to update key communities at risk or the general public about these changes in the past decade. Public health strategies and campaigns in Wales have not changed, with Health Boards concentrating on teenage pregnancies and no focus on HIV prevention or testing promotion. Along with the lack of online booking and postal testing (the latter until 2020) and general perceptions of long waits at urban clinics, perception of sexual health services among younger people can be poor.

## Stigma:

Stigma remains paramount in explaining why some people don't get tested for HIV. Other forms of inequalities (i.e., racism, classism, sexism, etc.) produce conditions which can amplify someone's fear of a positive test result. Across communities, perceived or internalised stigma can have a significant impact on a person's psychological state and fears of being stigmatised may prevent individuals from accessing HIV testing, prevention, care and support services[6] [7] [8] [9].

A number of organisations such as the NAZ project suggest that people from the BAME communities may decline an HIV test due to the fear and stigma that is associated with a positive diagnosis. They go on to suggest that stigma is a key barrier to why BAME people do not want to be tested for HIV and that the attachment of stigma varies between ethnic groups but also within them. HIV stigma within communities means that a HIV diagnosis has impact far beyond the individual who has been diagnosed which is why some people choose not to be tested due to the social implications associated with it[10].

## Funding:

In England cuts to local authority public health budgets have been severe. The Health & Social Care Committee's 2019 report[11] on sexual health gave a damning verdict on the impact these have had on sexual health services, with funding in certain parts of the country cut by as much as 40%. The Committee was explicit in its recommendation that 'Government must ensure sexual health funding is increased to levels which do not jeopardise people's sexual health. Inadequate prevention and early intervention increase overall costs to the NHS'. There has been no change in UK Government policy regarding public health spending with the Department for Health & Social Care yet to publish spending allocations for 2021/22.

6 Lorenc, T., Marrero-Guillamón, I., Llewellyn, A., Aggleton, P., Cooper, C., Lehmann, A., & Lindsay, C. (2011). HIV testing among men who have sex with men (MSM): systematic review of qualitative evidence. Health education research, 26(5), 834-846.

7 Prost, A., Chopin, M., McOwan, A., Elam, G., Dodds, J., Macdonald, N., & Imrie, J. (2007). "There is such a thing as asking for trouble": taking rapid HIV testing to gay venues is fraught with challenges. Sexually

8 Doyal, L., & Anderson, J. (2005). 'My fear is to fall in love again…'How HIV-positive African women survive in London. Social Science & Medicine, 60(8), 1729-1738.

9 Chinouya, M., Hildreth, A., Goodall, D., Aspinall, P., & Hudson, A. (2017). Migrants and HIV stigma: findings from the Stigma Index Study (UK). Health & social care in the community, 25(1), 35-42.

10 Back2BLAQUE symposium report 2018 – NAZ (2019)

11 https://publications.parliament.uk/pa/cm201719/cmselect/cmhealth/1419/report-summary.html

## Case Study:

*In Birmingham, we receive weekly report on patients who have not been offered an HIV test when engaging in any of Umbrella's sites. The report also provides the names of the clinicians (Doctors, nurses, HCAs, etc) who managed the patients' consultation on that appointment. We then provide individualised written feedback to our colleagues. Our standard practice is to recall the patients for having the test on site or through our home sampling service[14].*

Due to devolution and funding controlled centrally, we are unable to provide evidence of whether we have seen a reduction of funding in the services provided in Wales and Scotland. However, in Northern Ireland we have seen a restructure that has led to a cut in capacity and funding.

When these barriers are not a factor, many people are then not offered a HIV test.

In the UK there are robust guidelines that anyone presenting at a sexual health service in the UK should be offered a HIV test. The 2016 NICE guidelines[12] state 'Offer and recommend an HIV test to everyone who attends for testing or treatment', while the 2020 BHIVA guidelines state HIV tests should be offered to 'People attending health services whose users have an associated risk of HIV, including sexual health services.' Despite the clear rationale for offering testing, over 250,000 people in England leave a sexual health clinic without being offered a test annually, with total HIV testing coverage in sexual health clinics at only 65%[13]. There is currently no data on this for the rest of the UK.

Of the missed opportunities to test for HIV in sexual health clinics in England (PHE data 2020[15]), 75% were women; women are both less likely than men to be offered a test, and less likely to accept one when offered. Few gay and bisexual men declined testing (4%), in contrast to 9% of Black African heterosexual men and 20% of Black African heterosexual women. Combined with the 15% of Black African heterosexual women not being offered a test, this means over a third of Black African heterosexual women not being tested at a sexual health clinic.

In Scotland it is estimated that around 8%[16] of people living with HIV are unaware of their status. The Scottish Government's existing Sexual Health & Blood Borne Virus Framework[17] states that 'testing for HIV should not be exceptionalised.' A short-life working group[18] on HIV testing in Scotland recommended increasing the opportunities to test for HIV, noting that there is a "disparity" in access to sexual health clinics in Scotland, with some Health Boards only offering testing on weekdays with limited opening hours.

In Wales universal opt out testing is in place at sexual health clinics and in prisons. However, we do not know due to lack of data how many people opt out of having the test. Again, there is no access to most sexual health clinics out of weekday working hours, which renders them inaccessible to many of the public[19].

Personal risk also accounts for why some BAME people decline a HIV test; due to a lack of understanding about HIV many people feel they have not been at personal risk and that a HIV test is not needed. Why someone is visiting a sexual health clinic also plays a role in calculating personal risk as if they are attending solely for reproductive care rather than STI related care they are less likely to accept a test.

12 https://www.nice.org.uk/guidance/ng60
13 https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/943657 Impact_of_COVID-19_Report_2020.pdf
14 Kaveh Manavi Submission
15 https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/943657 Impact_of_COVID-19_Report_2020.pdf
16 Submission by Waverly Care
17 https://www.gov.scot/publications/sexual-health-blood-borne-virus-framework-2015-2020-update/
18 https://www.hps.scot.nhs.uk/a-to-z-of-topics/hiv/
19 Fast Track City Cardiff Submission

THT, NAT and EJAF suggest the reason why many people decline or are not offered a HIV test is down to stigma and outdated beliefs about HIV are also likely to play a significant part in this. We know many people still see HIV as a 'death sentence' and often say they would rather not know about a diagnosis as a result, impacting testing rates. This is why THT, NAT and EJAF emphasise that it is essential the modern realities of living with HIV as a long-term manageable condition are explained and communicated more widely.

## COVID-19:

BHIVA and BASHH stated in their evidence that COVID-19 has considerably limited access to walk-in testing services during lockdowns, with a BASHH national survey of sexual and reproductive health services finding that 54% of these had closed in April 2020. There was also a considerable drop (around 50%) in available staffing, with 38% of staff redeployed to work with COVID in-patients, and 17% shielding or sick. These values remained similar throughout the lockdown of January 2021 (BASHH Surveys April 2020-Jan 2021). The real impact of COVID on HIV transmission cannot be accurately assessed at this time but the survey evidence demonstrates that testing capacity has been significantly reduced within clinics as a result of the pandemic.

Restriction of public movement during lockdown has particularly impacted upon some at-risk minority populations without access to online services/experiencing digital poverty/living in multi occupancy households.

However, demand for postal HIV testing has increased, stimulated by campaigns such as National HIV Testing Week in England, which in 2021 serendipitously coincided with the impact of the Channel 4 It's a Sin TV series, a drama about the impact of HIV in the 1980s.

In Scotland, HIV Scotland and Waverley Care expressed concerns that COVID-19 has resulted in serious access issues to HIV testing. Sexual health clinics are closed for routine HIV testing at the moment and at-home HIV testing is only available within certain NHS Health Boards. The national HIVtest.scot recently closed for evaluation meaning Scottish people, like in England, rely on a postcode lottery and some cannot currently access HIV testing.

However, in Wales the swift pivot to a national postal HIV testing scheme for HIV in May 2020 following the first COVID-19 lockdown maintained and even increased testing, including testing by people who had not previously tested in clinics. This is the subject of a current evaluation for which data is not yet available but should be shortly.

Making testing easy to access and user friendly is key in getting more people tested and knowing their status.

## Summary:

Despite proper guidelines set out by NICE and BHIVA around HIV testing, many hundreds of thousands of people are either not offered a HIV test or decline one. HIV stigma continues to be the main reason understood as to why people choose not to have a test, as well as why health professionals may choose not to offer a test. However, lack of knowledge around HIV testing, including where to access a test and the benefits of testing seem to be a major barrier in getting more people tested in Wales, Scotland and Northern Ireland. This is why all submissions called for a UK wide information campaign on testing, PrEP and the realities of 21st century HIV.

We have seen how COVID-19 testing has been a success and that during lockdown and since the broadcast of Channel 4's It's A Sin, we have seen that more people across the UK have requested HIV testing, even when sexual health clinics have been closed.

As in Wales, sexual health services should move to an opt-out system of HIV testing, and no one should leave without being offered a HIV test. Data collection must be improved as to why people decline a test.

Getting a negative test should not be the end of the conversation, as is too often the case. Where someone receives a HIV negative result, either in a clinic or through a text message after completing a home sampling HIV test, information should be provided about how to access PrEP and condoms, as means to stay HIV negative, as well as regular reminders to test again in the future.

All healthcare professionals must receive regular and up to date training so that they are comfortable in having discussions and are confident to offer HIV tests to all their patients.

## Recommendations:

**1.1 Sexual health services should move to an opt-out system of HIV testing and no one should leave a clinic without being offered a HIV test and being signposted to at-home HIV testing services where these are available.**

**1.2 All clinicians and frontline staff across health and social care should receive regular training so they are confident in having discussions about HIV, HIV prevention and HIV testing. This training should also focus on the barriers to HIV testing including stigma, racism, transphobia and wider discrimination.**

**1.3 The reasons why people decline a HIV test need to be better understood and this data should be captured and made available throughout the UK.**

**1.4 There should be access to at-home HIV testing services across the UK, with a particular focus on rural areas which are often most underserved by sexual health clinics.**

**1.5 A National Campaign to educate the population on the benefits of PrEP needs to be formed and implemented.**

# Area: 2:
# Testing in Primary Care and Accident and Emergency Departments:

***"Making HIV testing available and normalised throughout the health service not only means people can be treated but by testing becoming routine, this removes some of the stigma that's holding us back" Sir Elton John[20]***

Evidence suggests that there remains considerable scope for increasing HIV testing opportunities in other parts of the NHS through a variety of interventions.

Universal opt-out testing in maternity services has demonstrated a high uptake and receptiveness to HIV testing, which, in turn, has ensured that many previously undiagnosed women have been tested and linked into HIV treatment services. There are clear benefits to the health outcomes for both these women and their children.

HIV tests are now offered as a standard part of the testing and health interventions delivered during peri-natal care. Providing the necessary information for women to make an informed choice in a non-judgemental, sensitive manner, has ensured the success of HIV testing programmes within maternity services. This approach needs to be replicated elsewhere, tailored as necessary to different health service settings.

Organisations that submitted evidence stated that what was important in the success was the support of providers for the approach, which saw a direct benefit for the clients in effectively treating pregnant women and their children. They argue that a similar perception and understanding must be created among other providers, specifically at the primary care level. If not, HIV screening by GPs and elsewhere will continue to cause challenges.

However, with introducing opt out testing into other parts of health and social care settings, there are challenges.

20 https://www.reuters.com/article/us-aids-britain-cases/elton-john-calls-for-wider-hiv-testing-to-end-new-cases-in-england-by-2030-idUSKBN28A2SU

Where HIV testing can be added as part of overall health checks, or as tests in response to presenting with indicator conditions, or by request of patients who simply want to test, there should be few logistical challenges. GP and primary care services already offer a wide variety of tests by trained clinicians who (should) have the skills and knowledge to deliver HIV testing.

There is evidence that many clinicians, including GPs, who do not have direct experience in sexual health or GUM clinic environments, lack the confidence, knowledge or skills necessary to offer appropriate HIV testing to patients, even when clinically indicated. This could be for reasons of a lack of training, work pressures or, at worst, personal prejudices and stigma about HIV and the behaviours associated with risk of HIV infection[21].

If HIV testing is to be successfully integrated into primary care/GP and other health services, it is imperative that nurses, doctors, and other health care staff feel informed and confident to discuss all the issues related to HIV prevention and testing, including risks, treatment, sexual activities, drug use, stigma and more. Training gaps and needs among staff must be identified and addressed. Training activities need not be expensive or a burden; the HIV NGO sector, with decades of experience in delivering expert knowledge around these issues, is a valuable existing resource that can be tapped into in most areas.

Opt-out testing in maternity services, and more recently in A&E care in some hospitals, has demonstrated that low uptake is not something to fear as a potential barrier. EJAF stated with their experience in Southwark, Lambeth and Lewisham that when HIV testing is offered in a normalised manner, with the correct information and support, the evidence shows that most patients will test. This is especially the case when offered as part of a package of testing and support, as in maternity services[22].

Emergency Department (ED) HIV testing is highly effective, with 119 people being newly diagnosed with HIV in the EJAF Social Impact Bond (SIB) testing sites at Kings College Hospital and University Hospital Lewisham (UHL) since November 2018. ED testing is especially effective in finding people with a late diagnosis of HIV, who are at heightened risk of poor health and onward transmission[23].

This model works in areas of high incidence of HIV, but there remains debate about whether ED testing is appropriate in areas of low incidence. It was EJAF, THT and NAT's and Others' view that as the number of people living with HIV reduces nationally, it will become more expensive to find each new diagnosis as more tests are required per positive result. However, without widespread opt out HIV testing, it will be impossible to reach the target of zero HIV transmission by 2030 and the gains from doing so become more significant as the overall total number of diagnoses decrease, with long-term significant pay-offs both for better health but also financially in preventing new transmissions.

21 BHIVA submission
22 BHIVA submission
23 EJAF submission

EJAF stated that they have seen clinician behaviour change when other clinicians share stories of success, whether that be diagnosing someone in ED whose profile would never have been otherwise considered for a HIV test, or a GP influenced by a lunchtime learning session to order HIV tests for patients, who diagnosed a person living with HIV within days of this. These testimonials reinforce the positive end results that can come from behaviour change, and they make things "real" by describing a person's own lived experience [24].

In was stated by Fast Track City Cardiff that links between sexual health services and GP surgeries are often under-developed and could be strengthened, including by basic tools such as sharing information leaflets and posters[25]. However, other submissions have pointed out also that this could be the case across the UK. Given the difficulties of geographical access to sexual health clinics for many Welsh people and a relative lack of awareness of the recent move to a national postal testing option, working with GPs and specialist peripatetic nurses, as is done in Powys, could help reduce regional inequalities and offer an accessible sexual health service across Wales or other rural areas. Access to testing and PrEP in both GP surgeries and pharmacies should also be explored, in the way that contraception is often managed. It was commented, though, that primary care services need to be willing to sign up to this at the top level for it to happen.

As we have seen with Covid, a small number of people living with HIV are concerned about telling their GP about their status. It has been argued by the HIV voluntary sector that confidentiality is often cited as a reason for restrictive practices around HIV when in reality it can be a shield against changing custom and practice. An example of this is the way in which medical records on sexual health are not customarily shared. Although in the past there were some reasons why people with HIV might not want to share their diagnosis with their GP, we are now in a situation where the majority of health needs of people with HIV can be managed by their GP. The most recent example of this is COVID vaccination, where HIV organisations had to campaign for a special exemption for the small number of people with HIV whose GPs are ignorant of their status, in order for them to access the vaccine at the appropriate time. It was argued by a number of organisations that unnecessary use of confidentiality can bolster stigma and, in fact, endanger health. Instead, HIV should be treated as what it has become for most - a chronic condition which, if properly managed, should not impact on most people's everyday lives.

If introducing HIV testing in new settings is to succeed, it was argued by THT, EJAF, NAT, BHIVA and BASHH that ensuring existing systems and processes embed routine HIV testing into patient care and foster good communication between primary and acute care about test results and consequent HIV treatment are vital. These may include automating the process of a clinician selecting a HIV test for their patient in the form of a pop-up message on a computer screen as a reminder to consider testing (though this may raise concerns of pop-up fatigue,) or a blood testing screen automatically selecting an HIV test unless cancelled by the clinician.

24 EJAF submission
25 FTC submission

It was also suggested that systems to introduce HIV testing must include thinking about how to enhance existing processes to ensure a newly diagnosed person receives good patient care. These include ensuring that HIV clinics have access to a listing of GP direct lines to follow up on patients, HIV clinics have templates for GP letters that are both clear about the actions that the GP needs to take and collaborative in tone, and HIV clinics have information about the local support mechanisms to help patients without a GP to register, particularly those who are most vulnerable[26].

## Testing and PrEP:

It is imperative that those who engage in high-risk behaviours and test negative are supported with the right information and tools to ensure they remain negative. Information on all prevention tools, including condoms, PrEP, mental health support, and more, must be made available at point of testing and during follow-up activities, where appropriate, to everyone who tests negative. As a minimum, referral to sexual health clinics for PrEP should be made for people who inquire about PrEP or who are assessed as at higher risk of HIV. Printed and online information on HIV prevention tools, including condoms and PrEP, should be accessible and appropriate and sent to clients who want the information.

It is important that healthcare workers discuss the combination prevention toolkit as part of their testing service, and that they are receptive to hearing why one option may be more preferable to the client. We must ensure that people know that PrEP works differently for different types of sex/bodies e.g. that event-based dosing is not suitable for receptive vaginal sex. This means being trans-inclusive and affirmative. Investment in researching community barriers including peer-led focus groups and surveys would help a better understanding of ways to support PrEP uptake.

## Summary:

The benefits of A&E testing are multiple. It helps to identify patients who are at higher risk of transmission, who have not accessed testing elsewhere or have been lost to follow-up in HIV services. EJAF stated that opt-out testing in the London boroughs of Lewisham and Lambeth has seen a reduction in admission of patients with late diagnosis of HIV from 55% of all HIV-related admissions to less than 10%[27].

In a hospital setting, treating HIV testing as a patient safety issue has merits, and allows governance systems to support, for example, in recording and investigating clinical incidents of missed or delayed HIV diagnosis[28].

Funding, however, is a major barrier and it is not clear who will fund expanded HIV testing in hospitals in high and extremely high prevalence areas to meet NICE and BHIVA guidelines on testing.

26 NAT Submission
27 EJAF Submission
28 Evaluating a pilot process for reviewing late HIV diagnoses in England and Wales - Authors: Ming Jie Lee et al https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7081807/)

Improving access to testing in non-sexual health settings is key for less densely populated areas.

A national information campaign should run, a 'leaflet on every doormat' (like the tombstone campaign) with new facts about HIV, the possibility that we can eliminate new infections, that everyone should know their status, where they can get tested, and what is PrEP and how to access it.

Along with a national information campaign to educate the nation, the four governments must ensure that they develop a strategy for recruitment, training, and retention of the HIV workforce, in clinical settings, local government and the voluntary sector.

If COVID has taught us anything, is that to provide testing in other settings is possible, and we should be able to do the same for HIV testing and access to PrEP.

## Recommendations:

**2.1 Opt-out rather than opt-in HIV testing must become routine across healthcare settings, starting with areas of high prevalence.**

**2.2 Any HIV Action Plan adopted by any of the four governments must include the development of a strategy for recruitment, training, and retention of the HIV workforce, in clinical settings, local government and the voluntary sector.**

**2.3 Training about HIV, HIV prevention and HIV testing including barriers to HIV testing, stigma, racism, transphobia and wider discrimination should be made mandatory across the NHS and social care workforce.**

**2.4 Funding should be made available to implement a programme of coordinated campaigns in the UK across the decade, to enable residents in the UK to know how to find out their HIV status and increase their awareness of combination HIV prevention.**

**2.5 All late HIV diagnoses must be investigated as a serious incident by the National Institute for Health Protection, working with BHIVA, NHS Trusts, Health Boards, local authorities, and Clinical Commissioning Groups.**

# Area 3: People presenting with HIV indicator condition should receive HIV tests:

***"Why is it important to test for HIV? For a start, hundreds of people a year still die here because they test too late. The earlier you know, the more you can do about it and these days the treatments are good enough to keep most people alive into old age" Lisa Power[29]***

Evidence suggests that there remains considerable scope for increasing HIV testing opportunities in other parts of the NHS through a variety of interventions.

Universal opt-out testing in maternity services has demonstrated a high uptake and receptiveness to HIV testing, which, in turn, has ensured that many previously undiagnosed women have been tested and linked into HIV treatment services. There are clear benefits to the health outcomes for both these women and their children.

HIV tests are now offered as a standard part of the testing and health interventions delivered during peri-natal care. Providing the necessary information for women to make an informed choice in a non-judgemental, sensitive manner, has ensured the success of HIV testing programmes within maternity services. This approach needs to be replicated elsewhere, tailored as necessary to different health service settings.

Organisations that submitted evidence stated that what was important in the success was the support of providers for the approach, which saw a direct benefit for the clients in effectively treating pregnant women and their children. They argue that a similar perception and understanding must be created among other providers, specifically at the primary care level. If not, HIV screening by GPs and elsewhere will continue to cause challenges.

However, with introducing opt out testing into other parts of health and social care settings, there are challenges.

29 https://www.huffingtonpost.co.uk/lisa-power/hiv-testing-week_b_2176718.html

BHIVA and BASHH suggest that:

- All speciality guidelines for indicator conditions should include an HIV test (including NICE guidelines). Virology and microbiology laboratories should offer Reflex testing on Hepatitis B, Hepatitis C, and Tuberculosis samples. HIV testing should be included in the routine care bundle for IC.

Indicator Conditions are often separated into two categories:

- Conditions that are AIDS defining – that indicate an impaired immune system
- Conditions that are strongly associated with HIV prevalence

The Europe-wide OptTest project identified 25 AIDS defining conditions and 49 other conditions strongly associated with HIV. There are 37 indicator conditions strongly associated with HIV and identified by UK BASHH HIV guidelines[30].

Of those diagnosed with HIV in 2019, over 40% were diagnosed late. Many of these people had several previous interactions with the health system where their HIV could have been diagnosed earlier, often due to an indicator condition. Far too often these signs are missed. The majority of people who have been diagnosed with HIV have visited a GP in the prior year; one study found that 62% of those who tested positive for HIV had visited an average of three times prior to their diagnosis[31].

Despite both BHIVA and now NICE guidance recommending that everyone with a HIV indicator condition should be offered a HIV test, this guidance is not implemented consistently. A review of ten UK studies reporting HIV testing rates in patients presenting with indicator conditions showed that just 22% received an HIV test[32].

There are a number of barriers to improvement in this area. There is often low understanding of the links between indicator conditions and HIV, or the higher prevalence of HIV amongst these condition areas in specialist clinicians outside HIV and sexual health[33].

As with GPs, there can be anxieties about offering HIV tests, and a feeling amongst some professionals that HIV is a health issue best dealt with elsewhere, such as in sexual health services.

Staff anxiety and concerns also act as a barrier to change as shown in the Time To Test report[34]. Outdated attitudes and understandings about HIV persist, even in the health system. A major concern of all those who submitted evidence was the lack of education and training for staff. This is a key barrier to rolling out greater HIV testing.

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30 BASHH submission
31 https://www.catie.ca/en/treatmentupdate/treatmentupdate-210/anti-hiv-therapy/uncovering-hiv-looking-indi cator-conditions
32 https://sti.bmj.com/content/90/2/119?ijkey=cac504b252d12eb3e84ac40f073f7d520b68abb4&keytype2=tf_ipsecsha
33 THT submission
34 https://www.bhiva.org/file/gMSwfxmXnFQeb/Time_to_test_final_report__Sept_2011.pdf

To ensure the effective delivery of HIV indicator condition testing, front line staff need support and training, as well as clear referral pathways for positive results, to both administer testing appropriately but also to ensure they have the confidence to overcome outdated barriers to testing in patients.

Like many aspects of HIV prevention and care in England, fragmented responsibilities for commissioning have certainly contributed to slowing progress on indicator condition testing. One of the first conversations which is often had when looking at rolling out testing into clinical areas is 'who will pay?'. Whilst technically indicator condition testing should be covered by Clinical Commissioning Groups/ICSs, those in the system remain unclear, and securing additional funding can be extremely challenging[35].

Where progress has been made, local champions have often championed the introduction of HIV tests in their service area. They have either worked around existing systems, seeking to introduce testing as part of current budgets without seeking relevant additional funding they would be entitled to for fear of being blocked, or argued for their specific case, rather than seeing more systematic introduction across whole providers or health geographies.

In 2012, 66.8% of eligible individuals with Tuberculosis (TB) were tested for HIV but following greater clinical leadership and priority in the system this climbed to 81.1% in 2013, in just one year. The reason was that routine HIV testing was included as a key performance indicator for this clinical area.

A lack of resources and it not being actively prioritised by commissioners in other clinical areas will continue to delay progress on increasing indicator condition testing unless directly addressed.

## Summary:

The latest report by Public Health England states that 4453 people were diagnosed with HIV in the UK in 2018. The number of people diagnosed late – many of whom may be in that 'harder to find' category – has also fallen, from 3353 in 2009 to 1883 in 2018 ('late' is defined as with a CD4 count below 350). However, because diagnoses in the recently infected have also fallen, the proportion of people who are late-diagnosed has remained fairly steady at 43%, (53% in Wales) and is much higher among some groups such as Black African heterosexual men (65%) and people aged over 50 (59%)[36].

In the latter case, this is partly because some people over 50 have simply had more time to live undiagnosed with HIV. The proportion of people diagnosed over the age of 50 years has increased from 13% to 21% in the last decade.

This is why all relevant medical Royal Colleges, NICE, medical faculties and professional organisations must review and update their guidance relating to indicator conditions. GPs must proactively test patients with indicator conditions for HIV.

35 THT submission
36 https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/965765/HIV_in_the_UK_2019_towards_zero_HIV_transmissions_by_2030.pdf

To ensure testing is carried out for those at risk and those with indicator conditions, training on HIV should be made mandatory for the entire health care workforce to improve the knowledge of indicator conditions and to address HIV stigma.

Without proper funding, guidance and training, testing those with indicator conditions will fall and more and more will be diagnosed late; this in turn will hamper the efforts to end new HIV transmissions by 2030.

## Recommendations:

**3.1 All relevant medical Royal Colleges, Faculties and other professional organisations to review and update their guidance on recommending HIV tests for patients with indicator conditions.**

**3.2 NICE should review relevant indicator condition guidance to include recommendations around HIV testing in line with existing NICE HIV guidance.**

**3.3 The four Departments of Health should provide additional clarity over commissioning responsibilities for indicator conditions and ensure resources are provided to enable testing and the training needed to deliver it.**

**3.4 Local commissioners across the UK to ensure they are providing resources to enable HIV indicator condition testing as part of the commissioning arrangements.**

**3.5 All four nations should review their policies and ensure clinical departments are consistently testing for HIV in patients presenting with indicator conditions.**

**3.6 GP practices, practice care networks and federations should ensure they identify patients with indicator conditions proactively, using GP records and data, and offer HIV tests to these patients.**

**3.7 The four nations should recognise unmet need in the sexual health sector and provide a radical uplift in public health funding, particularly investing in local sexual and reproductive health services.**

**3.8 As more people living with HIV access non-specialised healthcare, training on HIV and sexual health should be mandatory for the entire health care workforce to address HIV stigma and improve knowledge of indicator conditions.**

**3.9 The four Departments of Health and Social Care and their agencies, should collaborate more closely on the commissioning of sexual health and HIV services; and ensure greater integration of services to ensure seamless, patient-centred care.**

# Area 4:
# Ideas for implementation going forward:

***"It's a testament to the phenomenal progress we've made in our fight against HIV that we're able to conceive bringing an end to new transmissions in England within a generation. To get there we must find ways of tackling the appalling levels of stigma surrounding HIV, and significantly increase the reach of HIV-testing and other prevention activities." Deborah Gold – CEO National AIDS Trust[37]***

There are a number of examples of good practice and innovative HIV testing in primary and secondary care settings. From the submissions received there are a number of further specific areas for development. They are:

- Implementation of NICE and BHIVA Guidelines for HIV testing.
- Ensure HIV testing is part of a fully commissioned and funded service for all relevant conditions and settings.
- Encourage HIV testing as a routine part of outpatient blood tests.
- Basic HIV testing as part of mandatory training for all staff.

What are the lessons that we can be learn from the COVID response?

- The COVID response in A&E departments proves that we can offer universal screening for any condition in settings with high turnover.
- Executive level support has been instrumental in increasing HIV testing in Trusts and Health Boards.
- Cross-speciality working.
- The Shift to online HIV testing (92% of London boroughs have access to online HIV testing but offer of test is variable.) However, it should be noted that at least 20% of patients are unable to perform self-testing effectively[38].
- Remote consultations are now commonplace in sexual health services. However, we have yet to measure the potential negative impact of the COVID pandemic.

Many organisations have had to find new ways of outreach and support. Positive East developed and mobilised an assisted HIV self-testing service for East London residents to take HIV self-tests over Zoom or Microsoft Teams. During COVID they have seen an increase in heterosexual Black African men engaging with HIV testing in comparison to their engagement with the face to face service.

37 https://www.hivcommission.org.uk/2019/07/22/announcement-press-release/
38 BASHH Jan 2021 survey

They also saw first-time testers who do not feel comfortable accessing face-to-face services or have not been able to access them due to their limited opening times[39].

The COVID testing programme that has been rolled out across the UK is something that could be replicated for HIV, showing the diversity of testing sites, not just in a clinical setting and scalability of a testing programme and how quickly it can be rolled out. A variety of different sites have been used including pharmacies, libraries, drive-through testing and leisure centres.

Through all the evidence given it was emphasised that, as COVID restrictions lift in line with the varying government roadmaps, sexual health services and organisations need to keep doing what has worked well over the past year and continue to expand community-based and postal testing.

However, the potential negative impact of Covid 19 has yet to be measured when it comes to sexual health and HIV services, many of which have seen staff diverted to manage the newer pandemic.

The submission from Brighton & Sussex University Hospitals suggested that a 'click and collect' testing system should be rolled out to complement the postal testing scheme (which should be maintained post-COVID), to allow people to order a test when they have an unstable address or don't feel comfortable with ordering a test kit to their home address[40].

Fast Track Cardiff & Vale noted that the national move in Wales to postal testing had in fact increased testing overall despite little promotion of it beyond clinic referrals and their own social media. Continued funding and proper promotion of this service to primary care and communities most at risk could make a substantial contribution to reducing the higher rate of late diagnosis across Wales.

Fast Track Cities Cardiff suggested that the absence of timely data means it is currently not possible to plan services or target interventions to groups most at risk of acquiring HIV across Wales or in particular areas or to assess, for example, whether PrEP has had an impact on all groups at risk or whether some are being left behind. This is particularly problematic for Wales as a relatively low prevalence country, where accurate data could make a substantial impact in reducing onward transmission by targeting resources better.

COVID transmission does not have a criminal prosecution angle. Reckless or intention HIV transmission is a criminal offense. NAT and others argued that this law should be reviewed as it has not reduced HIV transmission. Instead, it has undermined public health by increasing stigma, victimisation and discrimination of people living with HIV. This is also a key challenge to increasing partner notification and a major barrier to testing. Knowing one's HIV status is positive places you at risk of prosecution. It's difficult to see how we can 'end new transmissions of HIV' with this law in place.

39 Positive East submission
40 BSUH submission

## Summary:

Ensuring that everyone, regardless of where you live, who you are, or what you do has equal and equitable access to sexual health services is critical in ensuring the UK meets the global targets and human rights obligations to guarantee that UK residents achieve the highest attainable standard of health and wellbeing.

To achieve this, a diversified approach to HIV testing delivery can help reach many communities, especially those underserved. By providing HIV self-testing as a complementary service to HIV self-sampling, the UK can ensure that the most underserved populations have equitable and equal access to HIV testing.

To increase HIV testing, responsibility for funding it needs to be clarified and streamlined in order to allocate it appropriately. We know that existing guidance has meant that implementation has been patchy and policies on opt-out testing need to be developed as part of the statutory obligation for services. Clearer policies would need to be introduced in conjunction with support for clinicians in the form of training around HIV and testing through an intersectional lens, through partnerships, working with sexual health clinics or voluntary organisations who can provide advice on how to approach testing with marginalised communities.

We have seen that the convenience of accessing COVID-19 through several avenues has been positive with walk-in test sites, home testing and app booking sites. However, there needs to be a level of caution when approaching this for HIV as it relies on the assumption that everyone has access to an electronic device and the internet. Digital health is not a magic bullet and a review is needed to see how it can be part of services in the future.

Collaboration and adaptation have been key to navigating the COVID-19 pandemic, we have seen industries adapt with many innovative ideas being developed. If we are to upscale HIV testing bold and innovative action is needed, along with commissioners, voluntary sector organisations and service users.

It has been 40 years since the first cases of HIV were identified. There have been huge advances in the treatment of HIV but in comparing the timelines it seems that the HIV response has been slow. Upscaling the response to HIV and testing programmes and reaching marginalised groups needs funding and political will to be in place.

## Recommendations:

**4.1** The UK Government working with the Welsh and Scottish Parliaments and the Northern Ireland Executive must review and assess the impact of current policies and legislation which act as a barrier to HIV elimination progress or where performance improvement is needed.

**4.2** Clarity is needed around where funding responsibilities for HIV mental health and peer support services sit.

**4.3** The four Governments should conduct a review to end digital poverty and exclusion.

**4.4** Existing HIV testing guidance should be fully implemented including routine testing for those with common indicator conditions

**4.5** Funding is required to appropriately resource the provision of HIV tests and the laboratory capacity to process them in a timely way.

# Area 5: Engaging under-represented groups in HIV testing:

***"The lack of visibility of men and women from Black, Asian and other Ethnic Minority communities in sexual health promotion has been well documented as having an impact on BAME sexual health and risk taking, which ultimately plays a role in the disproportionate rates of HIV infection in this population"***
***Marc Thompson - Director at The Love Tank[41]***

Improving testing uptake within underserved groups is a multifaceted task. Trust, shame, stigma and socio-economic inequality all need to be tackled. This report focuses on how these barriers affect uptake in testing in four groups: women, BAME people, sex workers and trans people. However, many of the comments also apply to underserved populations in general and these may vary from one area to another.

When considering underserved groups in HIV testing, there is a real need to recognise the breadth of diversity within the most at risk populations and see beyond that.

There are known barriers that these underserved communities continue to face in accessing health services in general. These include structural and systemic barriers which can lead to already marginalised communities feeling unwelcome, judged, or alienated. There is a wealth of evidence of the stigma faced by communities and the barriers this can pose to the uptake of HIV testing

## Women

Women make up a third of people with HIV across the UK, with an estimated 31,000 women living with HIV. As a group, women do not experience the best HIV outcomes: 44% of women diagnosed in England in 2019 for the first time were diagnosed late (above the average of 42%) and women are not experiencing the same rates of decrease in new diagnoses as some other populations. Women often say that they feel invisible in the response to HIV in the UK, that they feel ignored or not taken seriously by healthcare staff and researchers. Of the missed opportunities to test for HIV in sexual health clinics in England, 75% were women; women are both less likely than men to be offered a test, and less likely to accept one when offered. Women are nevertheless more likely to get their diagnosis at the GP, antenatal clinic or at other hospital outpatient departments.

41 https://www.gaytimes.co.uk/life/new-campaign-aiming-increase-hiv-testing-black-gay-men/

In 2017, Public Health England published its first spotlight report on women and HIV, following a recommendation from research conducted by Terrence Higgins Trust and Sophia Forum. The report noted that over the past decade the proportion of HIV diagnoses occurring outside of sexual health clinics and antenatal settings had increased from 17% in 2008 to 31% in 2017[42]. This suggests uptake of at-home testing options and community testing have increased over this time. The number of women attending sexual health clinics continues to increase as does the overall number of women who have been tested for HIV.

The majority of women testing for HIV in the UK are white (72% in 2017), with testing rates lower in other ethnic groups, with Black African women most likely not to be offered a HIV test and to decline a test[43]. Factors including structural racism within healthcare settings and a lack of staff confidence to have conversations about HIV with people from ethnic minority communities can contribute to people declining an HIV test. This underlines the importance of regular training and development that includes a focus on cultural competency.

The general consensus among the submissions was that opt-out testing is the only way undiagnosed women outside already targeted groups will get testing and learn their status. It must be routine and available in a wide range of services including A&E, registering with a GP and when the NHS is otherwise taking blood; the SIB in south London found an 87-year-old woman who would have otherwise gone undiagnosed. The success of antenatal opt-out testing, combined with the high rates of Black African women turning down a HIV test elsewhere underlines that the existing opt-in testing across the majority of healthcare settings is not working. Opt-out testing is the only way to address this problem.

The HIV Commission identified HIV testing during cervical screening and at termination clinics as important places to diagnose women in the UK. However, the guidance needs to be updated in line with BHIVA and NICE recommendations.

## BAME communities

We know that BAME communities, particularly Black African people, experience multiple barriers including institutional racism and bias in healthcare services. There can be a lack of trust in prevention and treatment, particularly around efficacy. There can also be cultural barriers and myths around treatment through prayer or herbal remedies.

People in BAME communities are overall more likely to be living with HIV, with Black African communities particularly disproportionately affected. Black Africans are identified by Public Health England as a key population for HIV, with 38 per 1000 living with HIV. Gender plays a big role too, with Black African women nearly twice as likely as Black African men to be living with HIV, with a prevalence of 51 per 1000, compared with 26 per 1000. BAME people are not only more likely to be living with HIV but are more likely to be diagnosed late with accompanying consequences for health. Black African (50%), Black Caribbean (48%), Black other (47%), Asian (46%), Other/mixed (40%) are the ethnicities most

42 THT Submission
43 THT Submission

likely to be diagnosed late. Since 2015, rates of late diagnosis amongst Black African heterosexual men have been rising, from 59% to 69% in 2017[44].

Evidence was presented that communities need to be further disaggregated in the approach to encourage HIV testing. For example, the experiences and needs of engagement for West Africans are different to those of East Africans. Furthermore, we see a rising prevalence amongst South Asian men who have sex with men and their needs are different to those of Black African and Black Caribbean men who have sex with men.

The APPG will be conducting an inquiry into the BAME communities and HIV later this year.

## Migrants

Some migrants with indeterminate immigration status fear accessing healthcare services will result in being reported to the Home Office, resulting in deportation. There may not be understanding that testing services and HIV treatment can be accessed for free. Additional cultural barriers may include stigma about sexuality and talking openly about sexual health. For most, English will not be their first language and communities may not see themselves represented within services, including those accessing and those delivering them.

Migrant communities may use drop-in centres or form community support groups especially if undocumented. HIV testing and prevention work should be embedded within a wraparound service for members of these communities using such spaces.

Recent Cardiff University research[45] states that HIV diagnosis is a taboo amongst “forced migrants” (asylum seekers and undocumented migrants) and that there are a unique set of barriers for public health. These include stigma and misinformation amongst the wider asylum seeking group; a lack of health education here; being forced to live in unsafe housing with other migrants who are homophobic and would react badly to them if they had HIV. Although asylum seekers are offered HIV testing on entry, they are not given the appropriate health education to avoid HIV once in the UK and, particularly for gay and bisexual men or those forced to supplement their income with sex work, there are heightened risks here. Reluctance to mix with the local gay population who may be racist or treat them as “exotic” may also cause them to miss out on what little information there is on HIV testing and PrEP.

### Case Study:

***Positive East has worked with RAMFEL and Aakwaba to increase their offer to include HIV testing to migrant communities, which include many people who hadn’t tested for HIV before[46].***

44 Public Health England submission
45 Vamvaka 2020
46 Positive East Submission

## Case Study

*"Other than being stuck with a discriminatory GP, my city only has one testing facility which means that appointments are very difficult to get, and my area isn't covered by any of the postal testing services (for example the THT). And on a more personal level, I present very masculinely, so attending testing appointments often leads to use of incorrect pronouns (even once I've corrected people and informed them I'm enby*) which makes the situation very uncomfortable to the extent that I dread attending weeks in advance of my appointments"*
**Non binary.*

## Trans people

Trans people with HIV gave evidence to the inquiry about the barriers they face in accessing HIV services and resulting poor HIV health outcomes.

Monitoring of trans identity is not consistently implemented across healthcare services, meaning that trans people are not identified as a population in need. However, within English sexual health services this is now recorded through CAD data since 2019.

Trans people report that they continue to be misgendered or placed in gendered wards that do not reflect their identity. It is important that assumptions are countered by registration documents which outline how clients want to be addressed including using non-gendered language to talk about the type of sex and body parts (e.g. anal sex, front-hole) when discussing the appropriate sexual health tests. Safety is also imperative to service access so services must ensure that there are policies and statements to assure people that transphobia will not be tolerated.

We learnt from community members that prejudice and transphobia remains present in some healthcare settings, in particular in those outside sexual health. Trans people are far more likely than the general population to report worse mental health and wellbeing, which combined with prejudice faced in healthcare settings, can impact HIV treatment and prevention[47].

The success and popularity of trans specific sexual health and wellbeing services including cliniQ and 56T, demonstrates the importance of having community led services. These services are often dependent on local NHS funding and trans specific services are often limited to larger cities in England. Where it is not possible to have a trans specific sexual health service, it is vital staff training is provided to support trans and non-binary people, including having conversations about HIV that are relevant to an individual.

## Where Next:

Other groups and communities are underserved in sexual health services, including those who are homeless or at risk of homelessness, those with substance misuse issues, mental health related issues and commercial sex workers. They may also possess multiple and intersectional identities such as being a migrant trans woman of colour, which will further compound experiences of navigating services, and how sexual health needs are considered.

47 Eli Fitgerald submission

BHIVA and BASHH in their submission set out what steps need to be taken to improve HIV testing amongst under-represented groups. They include:

- Increase opt-out testing in more settings
- Destigmatise HIV and increase awareness of the importance of knowing your status
- Targeted messaging in appropriate languages
- Communicate to migrants that HIV care is free and will not lead to deportation
- More testing in community settings led by community organisations and faith groups, working with these groups to seek their views
- Clearly identify trans inclusive services where they exist
- Better education and stigma reduction support by peer navigators and peer support workers.

BHIVA and BASHH recommend that a routine offer of HIV testing at least once every six months should be considered in services that engage with the following at risk and vulnerable groups:

- Alcohol and drugs support services, including chemsex drugs and substances
- Services for the homeless
- TB contact tracing programmes
- Patients requiring chemotherapy (haematology or solid organ tumours)
- Patients requiring immunosuppressive treatments
- Patients receiving transplants
- Patients with viral hepatitis (B, C)
- Patients attending mental health services
- Sex workers
- Migrants
- Heterosexual-identifying MSM.

When it comes to children, the Children's HIV Association (CHIVA) urged that the needs of children and young people should be considered in all testing strategies and that a repeat HIV test should be carried out later in pregnancy where there is an ongoing risk of acquisition of HIV.

## Summary:

Some have argued that interventions are not specifically targeted towards under-represented communities or tailored to their needs and that, when they are targeted, they are often homogenised as one group, not taking into account of the different intersectionalities that exist. Issues can include, homophobia, transphobia, interventions or services not being culturally, faith or language appropriate. This then adds to the barriers mentioned earlier in the report to communities engaging with HIV testing and sexual health services more broadly.

There was broad consensus that a lack of disaggregated data and research for all under-represented communities across data sets not just sexual health, means that the needs of those groups are not being met effectively.

Sexual health outcomes including HIV testing will not be improved in isolation and must be looked at through the wider lens of inequalities and should all be considered when developing the HIV Action Plan.

## Recommendations:

**5.1** **Services delivering HIV self-testing to under-represented groups in the UK should be implemented to support these groups.**

**5.2** **More tailored and targeted HIV interventions are needed to reach out to these under-represented groups.**

**5.3** **The four Departments for Health and Social Care along with the HIV voluntary sector need to engage with community-based organisations and faith groups that work within target communities to enable the facilitation of community testing.**

**5.4** **Interventions need to take account of the different identities that exist who need to be reached and be tailored and targeted to those specific groups.**

**5.5** **More research is needed to provide data on marginalised communities so as to better understand their needs. Disaggregated data and research would inform targeting, identify gaps and address barriers to testing more effectively.**

**5.6** **Anti-stigma campaigns and interventions to increase understanding, dispel myths and change attitudes towards HIV and HIV testing are needed to engage with the under-represented groups.**

**5.7** **Training and continuous professional development should be implemented for those working in a clinical setting to increase the knowledge and awareness of the healthcare workforce on HIV.**

**5.8** **An audit of public sector data sources should be conducted to establish where there are gaps in data collection and how data collection methods can be streamlined. This needs to be consistent across local authorities, Public Health Agencies and the NHS. Data needs to be disaggregated for BAME ethnicities in order to understand the needs of each group and where to target services.**

# Area 6: The future of online, home and community testing:

***"I think all of us working towards ending new transmissions of HIV by 2030 is a really positive thing as long as we don't forget those already living with HIV."***
***Darren Knight – CEO George House Trust[48]***

Although testing in a clinic is gold standard, there are many reasons why people are reluctant to attend clinics - stigma, geography, time availability etc as stated in section 1. It is imperative if we are to reach zero by 2030 that people are enabled to access testing in any way they feel comfortable.

Community HIV testing has long played a strong role in the delivery of HIV testing. Through voluntary organisations and charities, HIV testing has been brought to where people live, socialise, work and pray – including in commercial venues, festivals, churches, and events. This has reached people who might not have otherwise been tested, linking them into treatment, prevention and other sexual health services.

Home testing has more recently become a valuable option for many people who want to test and might not want or be able to access traditional or other face-to-face services. And there has already been some good success with home testing.

Even with successful community HIV testing programmes, there are practical barriers that need to be addressed. Some of these include:

- Funding and resources
- Awareness and availability of services
- Partnerships and referral pathways into treatment and clinical services.

Organisations such as NAZ, George House Trust, Positive East, Metro and HIV Scotland argued that community and home-testing services need to be supported, adequately funded, and integrated into planning strategies and delivery partnerships so that the successes they have already demonstrated are built upon and enhanced.

48 https://www.manchestereveningnews.co.uk/news/greater-manchester-news/its-sin-how-hiv-charity-19676295

### What is the provision of postal and self-testing in the UK?

At present the availability of at-home HIV testing depends on local authority services. In England, the only time testing is available across the whole country is during National HIV Testing Week. SH:24 operates free HIV testing at home all year round, with residents in 54 local authorities across England able to access the service. Sexual Health London provides free at-home testing for 30 out of 32 Boroughs in the city. This testing offer requires people to send a small blood sample in the post with results available a few days later by text or email. Access to testing in other parts of England remains inconsistent. A national ervice should be made available that offers flexibility for local authorities to do targeted work depending on local demographics[49].

Some local authorities, including Brighton & Hove, have introduced free HIV self-test kits (which provide a result within 15 minutes) for groups most at risk of HIV, including gay and bisexual men, and people originally from countries of high HIV prevalence[50].

In Scotland there is no national HIV self-sampling testing service. In April 2020 HIV Scotland and Waverley Care introduced a self-test service programme which is funded both privately and by the Scottish Health Boards, though not equally by all. This offers a self-testing option to all residents in Scotland. In under ten months 6,100 self-tests were ordered through this service. The Scottish Government has pledged to introduce a national online service for HIV and other STI self-sampling testing, in line with its ambition to end new cases of HIV by 2030[51].

Fast Track Cardiff & Vale stated that there is a proven appetite for postal and self-testing in Cardiff, and it is likely that this would be even greater in rural areas if access was advertised more widely. In the first six months of Wales' free national postal testing service, despite low levels of publicity, over 21,000 people requested postal sexual health tests of whom 60-70% requested HIV tests. This illustrates that the problem with testing is less a reluctance to test than a need for better access outside clinics.

In 2018, THT ran a short-term free offer of home testing to people in key populations at risk across the UK. Despite no particular targeting of Cardiff or Wales, Fast Track Cardiff & Vale state that these kits proved particularly popular. When local authority origins of those receiving kits was analysed, Cardiff had the third highest number after Manchester and Glasgow, both much larger cities with higher prevalence rates. Cardiff was also, with Salford, the joint highest source of reported positive results[52]. Fast Track Cardiff & Vale argue that this evidence shows a level of unmet demand for testing in the area.

Recently Cardiff University in collaboration with Fast Track Cardiff &Vale produced a report 'Getting to Zero' (2020)[53]. It reported on a range of local HIV service issues and preferences. In terms of how respondents would like to test for HIV in the future, self-testing was the most preferred option, closely followed by local

49 SH24 Submission
50 BSUH submission
51 Waverley Care submission
52 Fast Track City Cardiff Submission
53 https://fasttrackcardiff.files.wordpress.com/2020/11/ftc-reportv.2.pdf

clinics. Postal testing kits came next. If we consider both self and postal testing as "at home" options, this clearly takes the lead and the very strong uptake of the new postal testing scheme from Public Health Wales (as above) bears this out.

### What are the benefits and limitations of online/home testing for HIV?

BHIVA and BASHH in their evidence argued that an increase in usage of online services will lead to an increased capacity to provide face to face services for those patients whose needs continue to be best met in this way.

Where we have limitations to home testing, we also show benefits that provide us the opportunity to treat HIV like any other health condition. By normalising the testing process via a range of approaches to HIV testing, we can increase uptake and dispel a lot of the stigma associated with HIV. More so, by diversifying the approaches to HIV testing, it increases the frequency of testing among all communities, enabling people to learn their HIV status. However, more research is required to fully understand and enable better linkages to care through a home/self-testing programme and to better understand health-seeking behaviours among key population groups. Gaining a better understanding of these critical issues are necessary to ensure an effective home/self-testing initiative.

### Is it time for a UK HIV Testing Week?

National HIV Testing Week in England is currently managed by Terrence Higgins Trust. However, it was argued by a number of organisations that awareness and promotion need to be upscaled with national TV programmes, social media activities, and individuals from various backgrounds, races, ages, religions, and sex as part of the campaign[54].

National HIV Testing Week (NHTW) has been successful in several respects: increasing awareness of HIV, increasing awareness of the ability to test for HIV at home via self-sampling or self-test kits, increasing the number of people testing for HIV. Ahead of NHTW in 2021,a survey[55] by Terrence Higgins Trust found that 77% of UK adults had never had a HIV test, with uptake far lower in heterosexuals, where just 16% had previously tested compared to 57% of gay and lesbian respondents surveyed. There was a low level of awareness of HIV testing at home, with just 16% of adults knowing this was an option and with only 13% of those that had tested before, ever having actually tested that way. That is despite over half (58%) agreeing they would rather test at home during the lockdown than in a sexual health clinic[56].

Fast Track Cardiff & Vale found that most people in Wales currently rely on UK wide media or England-based media to receive HIV information. Around half of those who took part in a study by Professor Stephen Cushion, Cardiff University, incorrectly thought that changes in coronavirus regulations revealed by the UK Government also affected Wales.. A clear UK wide Testing Week would ensure a clearer campaign that resonates with all communities and would be beneficial in getting more people tested.

54 Positive East, Metro, George House Trust submission
55 https://www.tht.org.uk/news/77-people-uk-have-never-had-hiv-test
56 THT Submission

However, making any awareness week effective takes hard work and crucially money. It was stated in the majority of submissions that regional events and local engagement need to be at the heart of any Testing Week. The best way of making this happen is a collaborative approach resourced by multiple organisations, as with the Do It London testing campaign.

A single coordinated UK Testing Week would open the door for collaborative work between local groups across the four nations and those UK HIV charities who currently operate an England-only testing week. It could be used as a collaborative opportunity to engage other community based groups.

The preference by many organisations was for a UK HIV Testing Week that was aligned (as it originally started) with European HIV/Hepatitis Testing Week, because of the range of tools and support they offer to participants. However, it is important that the coordinated campaign across the nations should be when HIV testing capacity is relatively high, to meet the demand created by such a campaign.

## Summary:

With good planning, logistics and funding, community testing can have a bright future. Along with this, using community pharmacies or 'click and collect' points for tests would remove the need to set up a dedicated infrastructure

Fast Track Cardiff & Vale stated that in Wales data collection is disjointed, and for example it is currently not possible to link anonymised data relating to those who have ordered testing kits with test positivity results. This limits the utility of data from the Welsh National Postal Testing Scheme. We call for all four nations to create a unified HIV and AIDS reporting and data collection system on the lines of the internationally admired one currently managed by Public Health England. This system underpins national HIV surveillance and aims to inform public health responses, including identifying those most at risk.

Service providers and community groups all called for bringing testing data together from a number of different sources to ensure accuracy that will enable better targeting of resources.

It was also suggested that a collaborative approach should be adopted across all four nations in the provision of postal and self-test kits. Following this call, it is strongly advocated that a true HIV Testing Week that covers the whole of the UK should be created with all four governments funding it and with collaboration of organisations across the UK to ensure that the campaign is successful.

The preference that came out from the submissions was for the testing week to be aligned with European HIV testing Week, as this would allow a coordinated campaign when HIV testing capacity is high to meet the demand from the campaign.

To underpin all of this a National HIV Action Plan must be adopted by all four nations before the end of 2021 to ensure we can end new transmissions of HIV by 2030. Development of the plans must involve clinicians, NGOs and people living with HIV.

## Recommendations:

**6.1** **The flexibility and granularity of data collection systems must be maximised to meet the changing face of HIV and tackle inequity, including reporting on all communities.**

**6.2** **At a local level, existing processes of transferring patient information between sexual health clinics, secondary care and primary care should be examined to ensure best practice.**

**6.3** **Secondary care clinicians must have the resources they need to signpost and communicate with colleagues in other sectors effectively.**

**6.4** **Health and care systems must adopt innovations in a timely fashion, considering equitable access to innovation at every stage of planning and implementation. This includes telehealth, online testing and new biomedical technologies.**

**6.5** **The HIV Action Plans adopted by all four nations should include funding for opt-out HIV testing across the NHS, free at-home HIV testing available year round, a step change in health promotion programmes, action to reduce late HIV diagnosis and a new anti-HIV stigma campaign.**

**6.6** **There should be a coordinated HIV Testing Week across the UK, aligned with European HIV Testing Week.**

**6.7** **Digital infrastructures should be scaled up for people on low incomes and living in poverty, creating easier access to HIV testing and the wider healthcare system.**

**6.8** **Programmes, Campaigns and Services need to be co-designed with the communities they are trying to reach, so that the different cultures, languages, and faiths are accounted for.**

# Conclusion

As the number of people newly diagnosed with HIV in the UK continues to decrease, we will need to work even harder to continue the recent gains we have achieved. It remains essential that we normalise HIV testing with easily accessible HIV testing offers. We need to ensure we engage and identify undiagnosed cases in those who may not themselves identify as high risk but may have had past exposure, alongside the more traditionally targeted higher risk communities who are more likely engaged with their increased risk status. Targeted testing of higher risk groups continues to demonstrate huge successes in England, but will not capture all undiagnosed cases and barriers remain for many individuals. Better messaging and targeting needs to be had in Wales, Scotland and Northern Ireland if we are to reach the BAME, Trans, Migrant and Traveller communities.

Internet services have expanded rapidly over the last few years and have played an increasingly important part in ensuring continuity of access during the 2020-2021 COVID-19 pandemic. We have heard and seen that internet self-sampling services are being successfully used to engage and diagnose both higher risk individuals and those with more atypical risk profiles, by normalising testing and removing traditional barriers.

The World Health Organisation recommends that HIV self-testing should be offered as an additional approach to HIV testing services. Self-testing is not currently available within the Health Services in the UK, except in a face-to-face appointment in a clinic, but self-sampling is increasingly available. Both self-sampling and self-testing are known to be accurate, acceptable and feasible.

To do this, funding for tests needs to be secured. This will need a commitment from all four Governments. We also call on all the Royal Colleges (Emergency Medicine, Physicians, Surgeons, GPs, O&G, Nurses etc) plus BMA, BDA, NMC, GMC, GPC, HM Prison Service and all other governing bodies and Associations to sign up to the goal of reaching zero new transmissions by 2030 as a 'must-do' and disseminate information on this to their members.

If HIV testing is to be successfully integrated into primary care/GP and other health services, it is imperative that nurses, doctors, and other health care staff feel informed and confident in discussing all the issues related to HIV prevention and testing including risks, treatment, sexual activities, drug use, stigma and more. Training gaps and needs among staff must be identified and addressed. Training activities need not be expensive or a burden, with the HIV voluntary and NGO sector and their decades of experience in delivering expert knowledge around these issues being a valuable existing resource that can be tapped into.

In order to effectively increase HIV testing in the UK population, testing needs to be integrated into more services. For example, homelessness services should test people accessing their service. This will be particularly effective in reaching those who do not see themselves as being at risk, which is a large proportion of the population. This work should be prioritised and will require investment and support.

HIV stigma continues to be a reason why people choose not to have a test, as well as why health professionals may choose not to offer a test. It is essential that public facing campaigns on testing are mirrored by campaigns targeted at health professionals, even those working within settings where there is an assumed level of knowledge and value of testing.

A key lesson from the COVID-19 response in the UK that can be applied to the delivery of HIV testing is the way in which there was a rapid development of testing technologies and a rapid distribution of testing coverage to meet the varied needs of individuals and communities. Testing was rolled out in areas where people meet, work, travel, etc, ensuring that coverage was wide, convenience was enhanced, and uptake was high.

A second lesson is how COVID-19 testing was prioritised for those with health conditions which make them vulnerable to serious disease if infected with the virus. HIV testing also needs to be prioritised and routinely offered to patients diagnosed with related or serious conditions, namely TB, STIs and other indicator illnesses and conditions. Guidelines must be updated to meet those set out by NICE and BHIVA.

It is important that regardless of where someone has a HIV test in the NHS, when an individual's result is positive, there should be a clear referral pathway to local HIV support organisation for social support, wellbeing advice and guidance and connectivity to social prescribing to effectively manage the non-clinical/medical aspects of their HIV as independently as possible.

It is crucial that there are clear strategies, plans and investment to address the issue of under-represented groups and that it is truly targeted to individual groups and sub-groups of the population and 'easy' targeting using quasi-homogenous terms such as 'BAME' or 'LGBT' is challenged. It is essential that the target groups are identified and effectively targeted i.e., Trans Community, Black African Men, etc.

There is also a use of technical terminology and 'jargon' surrounding HIV that in the most part assumes a level of understanding that needs to be checked at all stages. All information needs to be in its simplest, most accessible format.

The UK is making good progress in its work to end new HIV transmissions. More and more people know their HIV status and this pattern will hopefully continue. However, this should not result in HIV dropping off the radar and no longer being seen as a priority. As more and more people know their status the cost per positive test will increase and this has to be recognised. If an increase in the detection of HIV cases is going to be achieved, budgets will need to be increased accordingly.

National HIV Testing Week is funded by PHE to support free testing for all during one week of the year for those living in England. However, there needs to be more consideration towards Scotland, Wales and Northern Ireland, who naturally become included in NHTW as they are part of the UK. There are no nationally funded testing weeks in these nations. There was overwhelming support for the four nations working together to hold a joint HIV Testing Week at the same time as European HIV testing week and that funding for this type of activity should be UK inclusive.

It is important that the new target of ending all new cases of HIV by 2030 is reflected in the language of national reports, as opposed to the UNAIDS 90:90:90 targets which we have consistently exceeded. The recommendations from the HIV Commission for England need to be embedded in surveillance along with accountability to achieve the targets. This includes a marked increased investment in testing, prevention and support services to maintain a reduction in new diagnoses amongst populations most affected by HIV. Alongside this the needs of people living with HIV and in particular those struggling to live well with HIV need to remain on the agenda.

Testing is one key tool in the fight against new transmissions of HIV, along with PrEP, Condoms and Treatment (U=U). We must ensure that testing and prevention have adequate funding, equality and equitable access and messaging, so that we can truly meet the 2030 target of ending new transmissions of HIV in the UK.

# Annex 1

## Sexual Health Provision in the UK

### England

Sexual health services are commissioned at a local level to meet the needs of the local population, including provision of information, advice and support on a range of issues, such as sexual transmitted infections (STIs), contraception, relationships and unplanned pregnancy.

Local authorities commission comprehensive open access sexual health services (including free STI testing and treatment, notification of sexual partners of infected persons and free provision of contraception). Some specialised services are directly commissioned by clinical commissioning groups (CCGs), and at the national level by NHS England for HIV.

### Wales

Public Health Wales (PHW) provides specialist public health resources at a national, regional and local level, including to Local Health Boards and to their respective Directors of Public Health. It provides centrally coordinated screening and health protection services for local health board populations, including the national STI and HIV postal testing service run through Frisky Wales.

Local Health Boards are responsible for all other testing service delivery and the health of the population in their areas, including local health promotion campaigns.

### Scotland

Across Scotland, HIV testing is delivered in a range of settings including sexual health clinics, community based services, via home test kits, and in other health care settings e.g., GP Practices. However, specialist NHS sexual health services remain the primary location for HIV and sexual health testing.

### Northern Ireland

Healthcare in Northern Ireland is regionally divided into 5 geographic areas, known as Health and Social Care Trusts.

Currently, sexual health and HIV services are available through 3 genitourinary medicine (GUM) clinics / sexual health clinics located in Belfast (the Belfast Trust), Downpatrick (the South Eastern Trust), and Derry/Londonderry (the Western Trust).

These Trusts operate under the guidance of the Department of Health (NI).

## The provision of postal and self-testing in England, Scotland, Northern Ireland and Wales.

### England

- In 2015 Public Health England (PHE) introduced a new framework for HIV postal-testing and appointed a provider for this service. Local authorities in the UK can sign up to the framework to allow their residents access to free HIV testing through www.test.hiv

- Not all local authorities have agreed to fund access to this service. Public Health England currently only funds national access at set periods of the year e.g. National HIV Testing Week.

### Scotland

- Scotland does not have a centrally organised HIV testing service like England.

- In April 2020 HIV Scotland and Waverley Care introduced a self-test service programme which is funded privately and by the Scottish Health Boards. This service offers a self- testing option to all residents in Scotland but is not equally funded by all Health Boards.

### Wales

- Public Health Wales provides home self-sampling tests for multiple STIs, However, this scheme needs to be secured post COVID.

### Northern Ireland

- Currently has no HIV self-testing programme in place. Residents are directed to testing through GPs or GUM clinics.

- Across all 4 nations there is no centrally funded option for self-testing, and therefore limited choice.

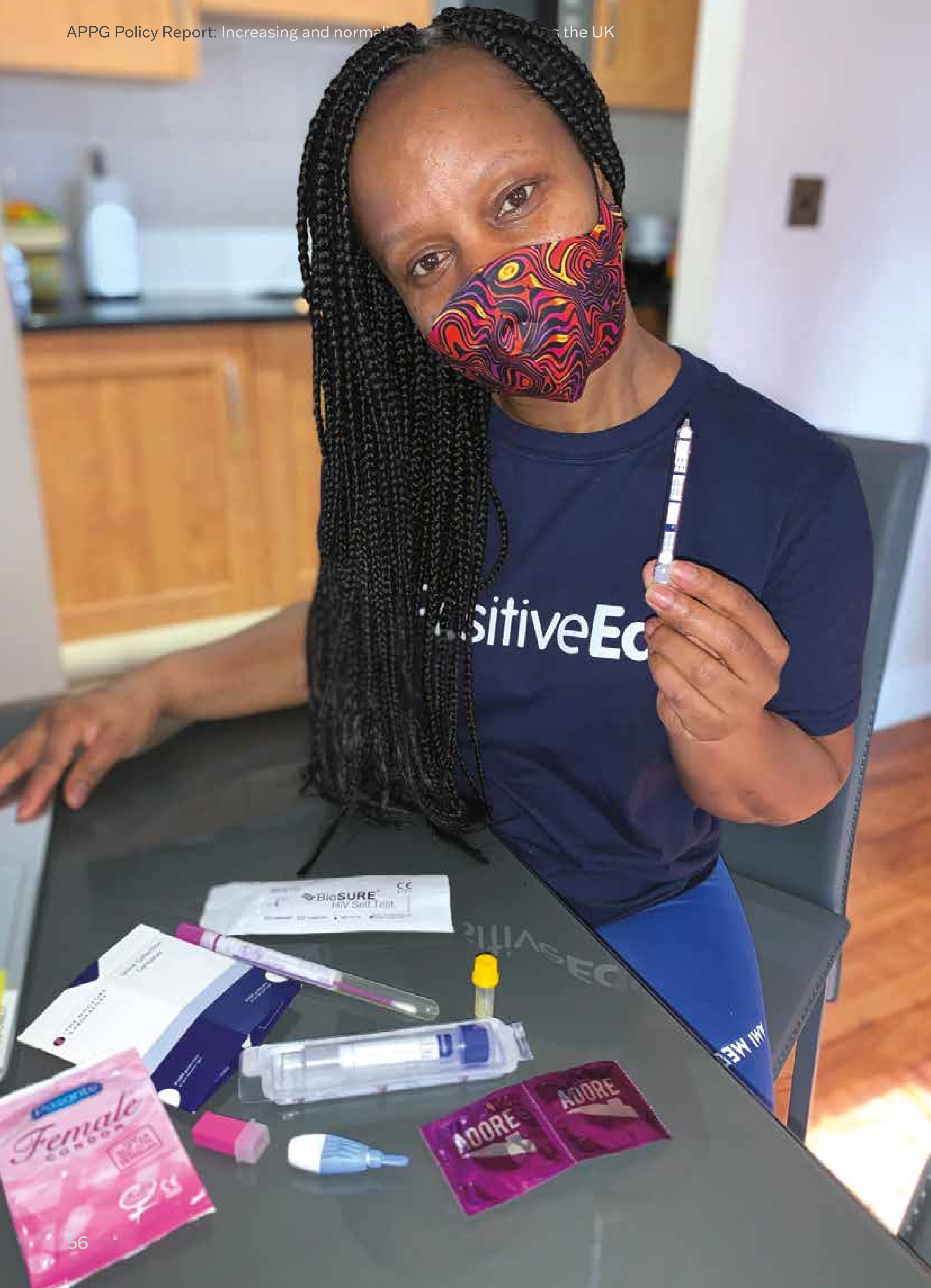
## Organisations who gave written evidence

- AIDS Healthcare Foundation UK
- BHA for Equality
- Brighton & Sussex University Hospitals (BSUH) NHS Trust HIV and Sexual Health dept.
- BHIVA
- BASHH
- Chase Ledl and Benjamin Weil
- The Children's HIV Association (CHIVA)
- Chris Sandford
- Rt Hon David Mundell MP
- Dr Clare van Halsema MSc MD FRCP Consultant & Clinical Lead in Infectious Diseases North Manchester General Hospital
- Dr Anatole S Menon-Johansson
- Eli Fitzgerald
- Elton John AIDS Foundation
- Fast Track City Cardiff and the Vale of Glamorgan
- George House Trust
- Greater Manchester Health and Care Partnership
- HIV Scotland
- National Institute for Health Research (NIHR) Health Protection Research Unit (HPRU) in Blood Borne and Sexually Transmitted Infections
- Jason Domino
- Kaveh Manavi - Deputy Chief Medical Officer
- LGBT Foundation
- Mark Ward
- Metro
- National AIDS Trust
- National Surveys of Sexual Attitudes and Lifestyles
- NAZ project
- Northern Service in Manchester
- Owen Mumford Ltd
- Pasante
- Positive East
- Positive Life Northern Ireland
- Public Health England
- SH24
- Sophia Forum
- Terrence Higgins Trust
- ViiV Healthcare
- Waverley Care

## Members of the APPG inquiry Committee

- Baroness Barker
- Lord Black
- Elliot Colburn
- Stephen Doughty
- Lloyd Russell-Moyle

# Notes


BioSURE
HIV Self Test
Female
ADORE
ADORE

# Notes

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