



HIV **COMMISSION**

HOW ENGLAND WILL END NEW CASES OF HIV

FINAL REPORT & RECOMMENDATIONS

TABLE OF CONTENTS

FOREWORD	4
ABOUT THE HIV COMMISSION	6
An innovative approach	6
Our values	7
Our Commissioners	8
Advisory Group	11
WHAT THE DATA SAYS	13
OUR TARGETS	19
OUR RECOMMENDATIONS	21
Stigma and Health Inequalities	23
Transformation	29
HIV testing	29
Adopting new technologies	42
Partner notification	44
Equity	45
Women	45
Gay and bisexual men	46
Black, Asian and Minority Ethnic communities	47
Young people	49
People who inject drugs	51
Trans communities	52
Meeting the equality challenge with the right data	54
Late diagnoses	55
Learning from failure	57
Resources	58
The HIV workforce	61
Access to HIV prevention and treatment tools	62
Leadership	68
Policy responses	69
Political leadership	70
Justice system	72
Local leadership	75
Partnerships	76
Partnerships	76
Integration of care	77
Commissioning	78
Managing complex needs	79
Mental health	80



CALL TO ACTION	84
APPENDIX 1	
The Advisory Group.....	84
Members of the Advisory Group.....	84
Co-Chairs.....	84
Academics.....	85
Community-based organisations: Representation from organisations addressing the needs of most at-risk communities	85
Government / Statutory: Representatives from national and local government and statutory organisations	85
Medical practitioners / clinicians.....	85
Supporting Members of the Advisory Group.....	85

FOREWORD

The HIV sector is a remarkable blend of optimists and pragmatists. Despite a decade of cuts and the fragmentation of the system followed by the 2012 Health and Social Care Act, there is a unity of purpose: to end HIV transmissions in England by 2030. This government commitment led by Health Secretary Matt Hancock is achievable by building on the pioneering work of people living with HIV, campaigners, HIV charities, expert healthcare professionals and the Fast-Track Cities initiative.

Despite progress so far and best intentions, England is not yet on track to meet the 2030 goal. This commission, having heard from experts from all walks of life and inspiring people living with HIV, provides a pathway towards meeting this ambition.

COVID-19, another global health challenge, has emerged during the life of the HIV Commission. We received evidence and considered its implications closely on the public health system and HIV. This report reflects this learning throughout. COVID-19 has shone a light on many of the same health inequalities that have been laid bare throughout the HIV epidemic. Addressing them will be essential and has significant benefits across a number of national health challenges. Equally, the impact from COVID-19 on the public health system could be long-lasting, and this must not blow off course the UK's strong progress on HIV.

It is our view that driving towards this date is not enough; the Health Secretary must share our aspiration of England's role as global leader and affirm his commitment to be the first country to end HIV transmissions. To ensure we are making sufficient strides to make this happen, England must adopt a crucial milestone: an 80% reduction in transmissions by 2025. Taken together – the 2025 milestone, the 2030 goal and a desire to be the first country to zero – history will be in the making.

If the government is serious about this policy, it will report to parliament annually on the progress England is making in each area. We believe that the Department of Health and Social Care and the Cabinet Office should be jointly responsible for this important task and driving government-wide change. Responsibility and accountability go hand-in-hand.



The message from the HIV Commission is 'test, test, test'. To find the estimated 5,900 undiagnosed people living with HIV in England, HIV testing must be normalised throughout the health service. Everyone should know their HIV status.

Read the full report at
www.hivcommission.org.uk/report

The message from the HIV Commission is 'test, test, test'. To find the estimated 5,900 undiagnosed people living with HIV in England, HIV testing must be normalised throughout the health service. Everyone should know their HIV status, and there needs to be equitable and easy access to this knowledge.

When patients register for a GP, present at A&E or when the NHS takes blood samples across all kinds of healthcare settings, there must be an offer of an opt-out, not opt-in, HIV test. Failure to make this change is missed opportunity upon missed opportunity to diagnose every case of HIV and stop preventable transmissions. Stopping late diagnosis is good for the health of people living with HIV and prevents new infections, while saving money by preventing declining health outcomes and the costs associated with long term care.

Maternity units show how transformative 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. The rest of the NHS must follow their example and similar results will be forthcoming.

Beneath these insights sits a 20-point plan of action. It is a comprehensive guide to how the government, NHS, public health officials and the voluntary sector can bring about the system changes needed to end new transmissions before the decade is out. We have just over 500 weeks to achieve our goal; it requires a new focus on tackling stigma, discrimination and health inequalities within the system.

If we get this right, England will not just have closed a chapter domestically on a five-decade long pandemic but stand tall as a global pioneer.

If the government embraces this commission's recommendations as it did the commission's

foundation, we are in good hands. I know they, along with everyone involved in the Commission, are indebted to the Terrence Higgins Trust, National AIDS Trust and the Elton John AIDS Foundation for having the foresight to instigate such an intervention.

I want to thank all three organisations, who have truly gone above and beyond, as well as everyone who has taken the time to submit evidence, shown us around their local services, or shared their personal and powerful stories.

Thank you too to the expert advisory group upon whose expertise and knowledge we have closely drawn. Finally, to my fellow commissioners – who have each brought passion, professionalism and precision to this process – I am immensely grateful for your contribution. The report reflects the commitment from each and every member.

Publication of these recommendations is only the beginning for them – we now must see a comprehensive HIV Action Plan as promised by the government. The HIV community will, I am sure, watch closely on their response to this report and hold decision-makers to account to ensure implementation is prompt and comprehensive.

I went into the process daring to dream about what can be achieved. Following the fifteen months leading this commission of remarkable people, discovering the potential of this remarkable sector, I count myself among the optimists and pragmatists.

I commend to you the HIV Commission's final report and its recommendations and action plan. The message to the government is now clear. Read. Adopt. Implement.



Dame Inga Beale
Chair, HIV Commission

ABOUT THE HIV COMMISSION

An innovative approach

The HIV Commission is an ambitious, independent process to find the path to ending new HIV transmissions and HIV attributed deaths in England by 2030. This Commission – our founding partners and the Department of Health – believes this is an achievable goal which requires energy and commitment.

The HIV Commission consisted of twelve Commissioners, all leaders in their fields beyond the HIV sector, who committed to working together to explore the issues and find solutions. They brought fresh eyes and leadership to old and new challenges. The HIV Commission launched a call for evidence open from November 2019 – January 2020 (targeted at organisations) and opened the 'Have Your Say' portal (targeted at individuals) from February to May 2020. We received ninety-seven written contributions of evidence across these two consultations. In February and March 2020, HIV Commissioners also held five public meetings across England, to talk to local stakeholders and community members, to understand the different regional responses to the epidemic.

On visits to Birmingham, Brighton and Hove, Bristol, London and Manchester, HIV Commissioners attended local HIV clinics, sexual health services and support services, and all included open public meetings in which Commissioners discussed the local landscape, problems and solutions with attendees. Alongside written and oral evidence from the public, an expert Advisory Group authored twenty-seven evidence papers, to brief HIV Commissioners on key topics related to HIV transmission in England. The writing of these papers represented an unprecedented level of cross-sector collaboration. This formed the evidence base for our recommendations and this report.

As the evidence-collection process was coming to an end, the COVID-19 crisis changed every aspect of life in England and across the world. The pandemic has held a mirror up to our society, drawing attention to long existing inequalities and costing lives. No report on solutions for the next ten years can ignore this change. The Commission has worked with a wide range of stakeholders to understand the impact of COVID-19 on prevention and care in England, reflecting this learning throughout this report.

Why a commission?

As a tried and tested model for influencing change, a commission brings a level of independence from government, statutory bodies and service providers in order to constructively challenge preconceptions and the status quo.

Who established it?

The HIV Commission was an independent process supported and funded by National AIDS Trust, Terrence Higgins Trust, and Elton John AIDS Foundation. The organisations used their convening power to combine the expertise and resources of new and existing cross-sector partners to end new HIV transmissions in England, through collecting evidence and developing recommendations.

Our values

We know that the fight against HIV has always also been a fight for social justice. In the last 10 years, campaigns for PrEP, resistance to stigma and demands for services have all sought to redress underlying inequalities that have been a part of the epidemic since its beginning. It will be impossible to end the HIV epidemic without also fighting racism, homophobia, transphobia, sexism, xenophobia and ageism, whilst considering all their intersections.

The response to HIV has always been foremost a community response, with activists working alongside clinicians, academics and government, in a way that is unique in the context of public health in England. This is because people living with HIV and their allies have had to work to get recognition that their health and their lives matter. The work of this Commission rests on the shoulders of those who fought and continue to fight these battles. Without them, we would not have reached a place where no new HIV transmissions or HIV-related deaths in England by 2030 is an achievable goal.

The COVID-19 crisis of the last few months has reiterated how existing inequalities are exacerbated in the face of an epidemic, with tragic consequences. As the world continues to fight COVID-19, there is lots to be learnt from the central role community has played in the HIV response. There is also much still to be learnt for the HIV response to be successful in the next decade.

Just as HIV disproportionately affects some communities, progress in reducing new HIV transmissions and improving outcomes for those living with HIV has not been equal across all key population groups. To end all new HIV transmissions by 2030 this must be addressed – and no one community can be left behind. If we are successful in ensuring that new transmissions in the UK fall, preventing and finding new cases of HIV will only become harder. However, this is not a case of diminishing returns; each case prevented or found will have a more significant impact on ending new transmissions. That is why our recommendations and this report places tackling inequalities and ending stigma at the core of what must be done to end new HIV transmissions by 2030.

Our Commissioners

In July 2019, a group of high-profile leaders from across society came together to help find innovative approaches to end new HIV transmissions in England.



Dame Inga Beale (Chair)

British businesswoman and the former CEO of Lloyd's of London

I went into the process daring to dream about what can be achieved. Following the fifteen months leading this commission of remarkable people, I commend to you the HIV Commission's final report and its recommendations and action plan. The message to the government is now clear. Read. Adopt. Implement.



Dr Rob Berkeley

Founder and Managing Editor at BlkOutUK.com

The HIV Commission has put tackling health inequalities at the heart of our work and findings – deliberating during lockdown due to the COVID-19 pandemic made it impossible not to be sensitive to the ways in which social inequality can be amplified by a virus. This summer many of us took part in demonstrations reminding our decision makers that Black Lives Matter and each other that 'Nobody's free until everyone is free. Similarly, progress in one HIV-affected community is not good enough unless it is experienced across all HIV-affected communities – our new targets reflect this. LGBT people of colour need the same access to PrEP, testing and HIV services, as do Black African women and trans people. Our recommendations will enable the government to show how it has learned from the challenging circumstances of the coronavirus pandemic.



Steve Brine MP

MP for Winchester and Chandler's Ford. Former Parliamentary Under Secretary of State for Public Health and Primary Care

Making the zero pledge was really important to me in office, as the Public Health Minister, so it was a great (and rare) chance to follow that through from the outside.

The HIV Commission put together a team, under a strong Chair, which it was impossible to refuse and I've found it both stimulating and challenging to be a part of it. I think we've set the bar high and our recommendations are every bit as ambitious as I hoped for at the outset.



Rev Steve Chalke

British Baptist minister, Founder of the Oasis Charitable Trust

It has been my privilege, over this last extraordinary year, to be part of the HIV Commission – a diverse and multi-talented team brought together with a single task: to focus on what it will take to end new HIV transmissions in England by 2030.

Together, we've had the opportunity not only of listening to, but reflecting on the expertise and insight of a huge spectrum of those who feel just as passionately as we do that, though ambitious, this life-changing goal can, indeed must be achieved.

And, as we've worked to shape and hone what is now a highly focussed and immensely practical set of recommendations, we have become more convinced than ever that, if we accept the challenge they present us with, and if we work together across society – government and policy makers, health commissioners and practitioners, local communities and people living with HIV – this is a battle that we will win!



Joshua Graff

UK Country Manager & Vice President EMEA & LATAM at LinkedIn

Over the last year, I have had the privilege of meeting some of the most dedicated, compassionate and inspiring people working in the HIV sector. From community workers in Brighton who host the weekly radio show 'HIV Hour', which helps to tackle the stigma and isolation many people face with HIV, to a nurse in Birmingham who often, out of her own pocket, buys milk for her patients living with HIV who have recently given birth and cannot afford it themselves.

Despite the many challenges they face on a daily basis, I've been struck by their optimism, resilience and determination to make a difference. I'm confident that with this incredible community, alongside rapid adoption of the Commission's recommendations, notably routine testing and political accountability, we have a unique opportunity to end HIV transmissions in England by 2030.



Dr Richard Horton

Editor-In-Chief of The Lancet

This commission is an opportunity to accelerate progress towards an HIV-free world. This ambitious goal will take a whole-of-society commitment. It was a privilege to work alongside leaders in our community outside of the health sector.

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Mehmuda Mian

Associate Director of
the Lokahi Foundation

As a Commissioner for the HIV Commission, I have particularly enjoyed meeting with and learning from those living with HIV. Hearing of their experiences – both positive and negative – and discussing possible improvements, and solutions has been inspiring. I especially want to thank the practitioners working within the health and support agencies who have contributed to the work of the Commission.



Dame Alison Saunders

Dispute Resolution Partner at
Linklaters. Former Director of
Public Prosecutions and Head of
the Crown Prosecution Service

There is no silver bullet in ending HIV transmissions in England but the experts tell us routine testing across the NHS comes close. We need to normalise the process of HIV testing when you join a GP practice, present at A&E, and when the NHS takes your blood in many other health settings. Despite the fragmentation of the system, national leadership can fix the barriers to more routine testing if there is the political will to make it happen.



Mercy Shibemba

HIV campaigner and
winner of the inaugural
Diana Award

As a young person living with HIV, it was a delight to be part of a process that cut across disciplines to consider what it will take to find ambitious and achievable ways to end new HIV transmissions in England by 2030.

The importance of the voices, experiences and thoughts of people living with HIV, remained at the centre and focus of the process. I was continually inspired and grateful for everyone who contributed. I look forward to seeing how the recommendations influence change and inspire an innovative path that will help us all on the journey.



Wes Streeting MP

Member of Parliament
for Ilford North

We can do this. We can end HIV transmissions within a decade. That's the clear and resounding message we've heard back during the course of our work and the reason I was so excited about joining the Commission. So many individuals and organisations have engaged with us and told us what needs to be done to make this ambition a reality – test, test, test is the resounding message. This report has the potential to be life-changing and history-making. We now need to make sure it happens.



Gareth Thomas CBE

HIV advocate and former
Welsh rugby captain

The HIV Commission understands HIV-related stigma is an urgent challenge if England is going to put in place the testing, HIV diagnosis and routes to effective treatment that will make ending HIV transmissions possible by 2030. Every Commissioner is committed to tackling HIV stigma and will watch like a hawk the progress being made and hold the government's feet to the fire as we all try and meet this ambitious and life changing goal.

Advisory Group

An expert Advisory Group, of over 40 topic experts representing different sectors in HIV treatment and prevention provided invaluable support to the HIV Commission throughout the process. This group included representatives from academia, community members, community-based organisations, government and statutory bodies, medical practitioners and clinicians. The full list of experts can be found in Appendix 1 and online: www.hivcommission.org.uk/advisory-group/.



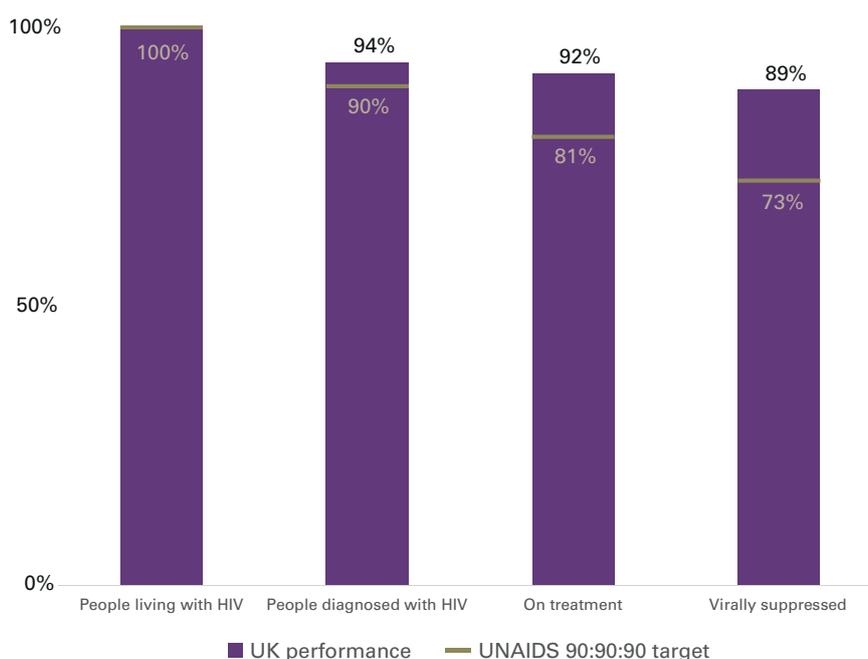
WHAT THE DATA SAYS

At the beginning of our journey as an HIV Commission, we reviewed published evidence and heard from leading HIV specialists about the current shape of the epidemic. Later, we reviewed and discussed the latest annual HIV statistics published by the HIV surveillance team at Public Health England. A team globally recognised as being first class that has provided us with data to inform our work across the year.

This work must be a priority for the newly created National Institute for Health Protection. The graphs below show the current data we have on HIV in the UK – who is affected and how – which served to frame our understanding and our findings. However, the data we do have falls short of what is needed. In our actions below, we highlight what data improvements we need to end new HIV transmissions by 2030. In order for our response to be agile as new HIV transmissions fall, we need more granular data which is easily accessible to everyone. Particularly, we must better collect data on more subpopulations by unpacking the ethnic category ‘other’ to really understand who is affected by HIV (see Action 7).

This category refers to multiple ethnic groups, so we still do not fully understand who they are and how to address their needs. Having a better understanding of who within this group are affected by HIV will be crucial to best inform the design of treatment and prevention initiatives to end new transmissions. There has been significant recent progress in HIV outcomes in England. The United Nations Programme on HIV/AIDS (UNAIDS) set a series of international targets to help end the pandemic – the UNAIDS 90:90:90 targets include that:

- ▶ By 2020, 90% of all people living with HIV will know their HIV status.
- ▶ By 2020, 90% of all people with diagnosed HIV infection will receive sustained antiretroviral therapy.
- ▶ By 2020, 90% of all people receiving antiretroviral therapy will have viral suppression.



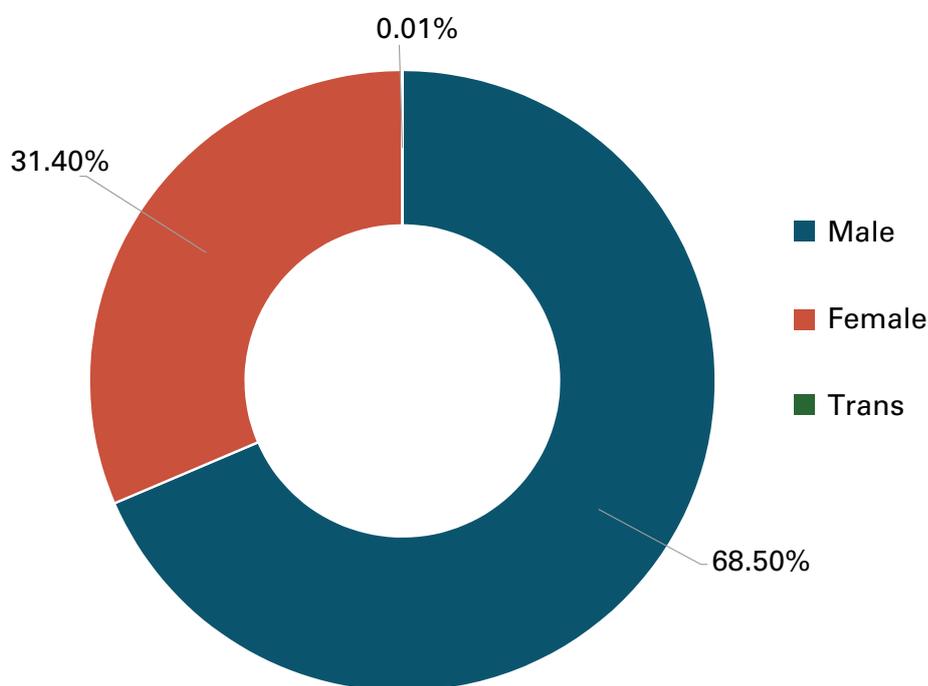
England's performance towards UNAIDS 90:90:90 targets, 2019

In England in 2019, 94% of people living with HIV have been diagnosed, 98% of those are on treatment, and of them, 97% are now 'undetectable'. The success shows what is possible and why complacency now would be a big mistake as we look forward to our 2030 ambition.

The most recent estimates suggest that in 2019 there were 96,200 people living with HIV in England. Of these, around 5,900 are undiagnosed in England – by definition they do not know they are living with HIV. Late diagnoses cause complications for the individual and risk preventable new HIV transmissions. While anyone can get HIV, some populations are disproportionately affected. In England, gay and bisexual men and Black African people continue to be the most acutely affected by HIV. We also know that London has consistently had the highest rates of HIV in the country, making up 40% of new diagnoses in 2019. Patterns of HIV transmission are not static and the people most at risk can change over time. We must be ready to respond to these changes.

Since 2014, there has been a decline in the number of people diagnosed with HIV each year (new diagnoses) and a decline in the number of people that Public Health England estimates to have acquired HIV each year (incidence rate). These declines have not been spread equally amongst all key population groups or across regions.¹ The most significant drop has been amongst white gay and bisexual men living in London, aged 25 to 49, increasing numbers of gay and bisexual men born abroad are more likely to be diagnosed with HIV than those born in the UK.²

The number of new diagnoses each year is sometimes used as a proxy for incidence (the number of new transmissions which actually occurred). New diagnoses and incidence rates are however different. A short-term rise in new diagnoses would occur if testing becomes routine in the health service (see Action 4) and we are able to find more of the undiagnosed people living

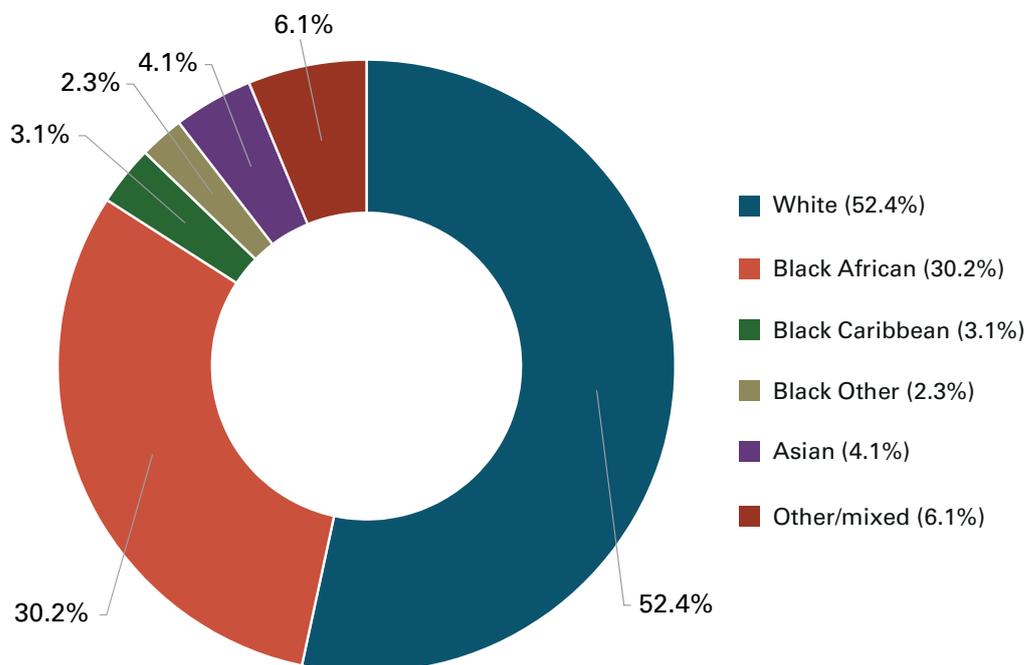


Gender of people accessing care in England

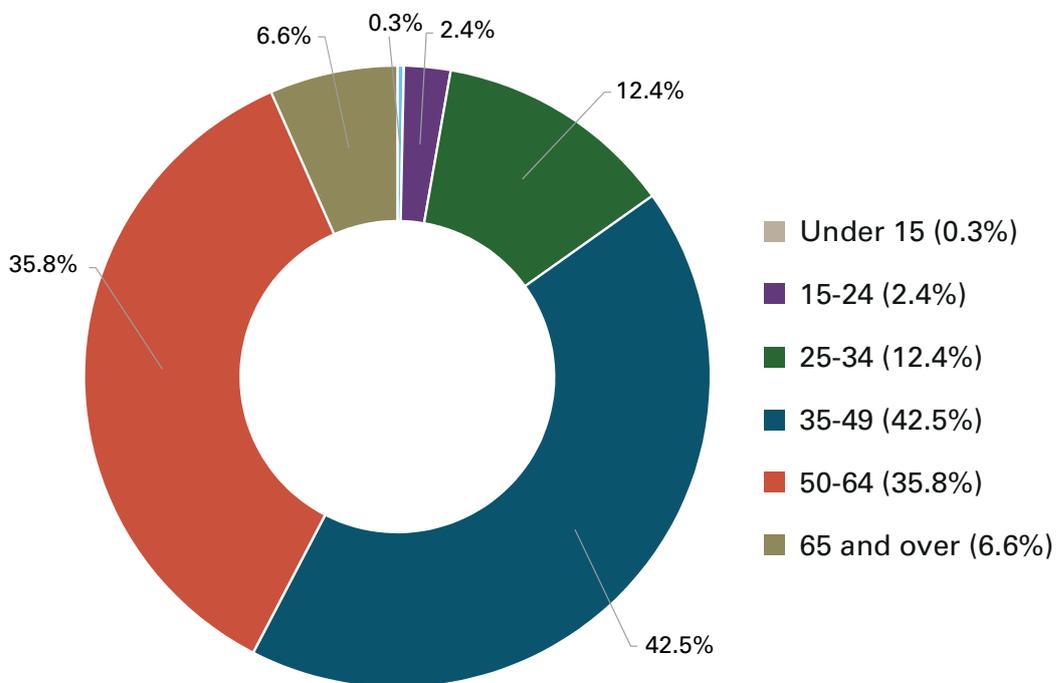
¹Public Health England, *HIV in the United Kingdom: Towards Zero HIV transmissions by 2030*, 2019

²Public Health England, *HIV in the United Kingdom: Towards Zero HIV transmissions by 2030*, 2019.

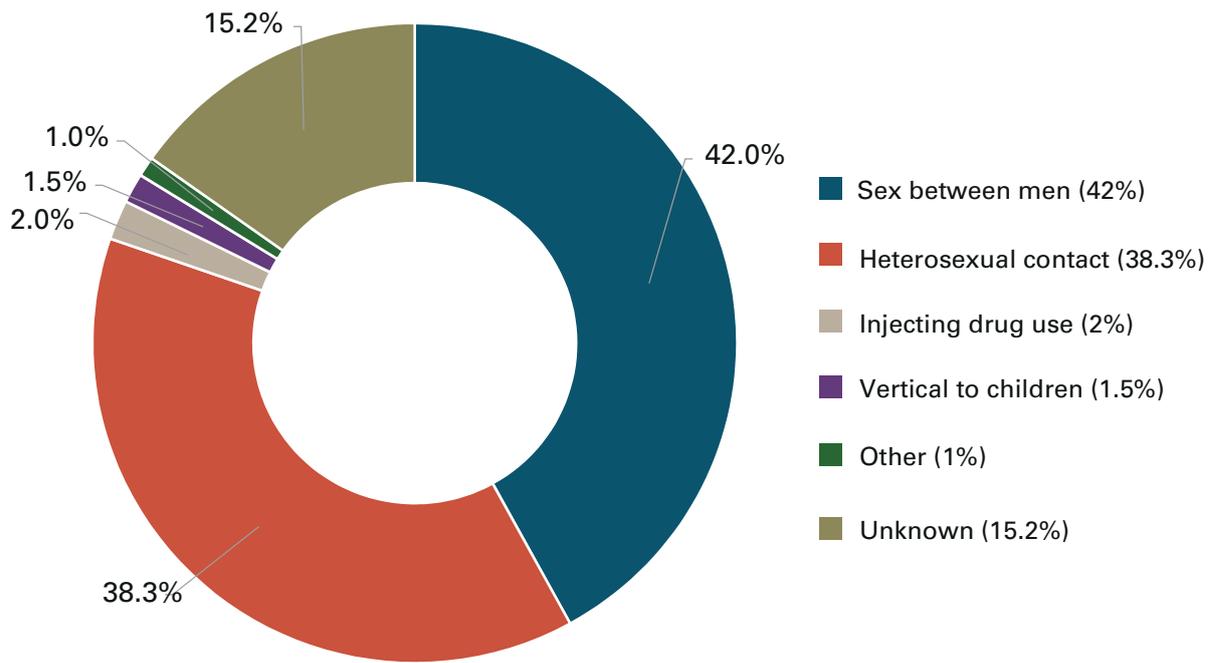
with HIV. This would be a success not a failure. For this reason everyone serious about ending new transmissions must track our progress against estimated incidence of HIV, not new diagnoses alone.



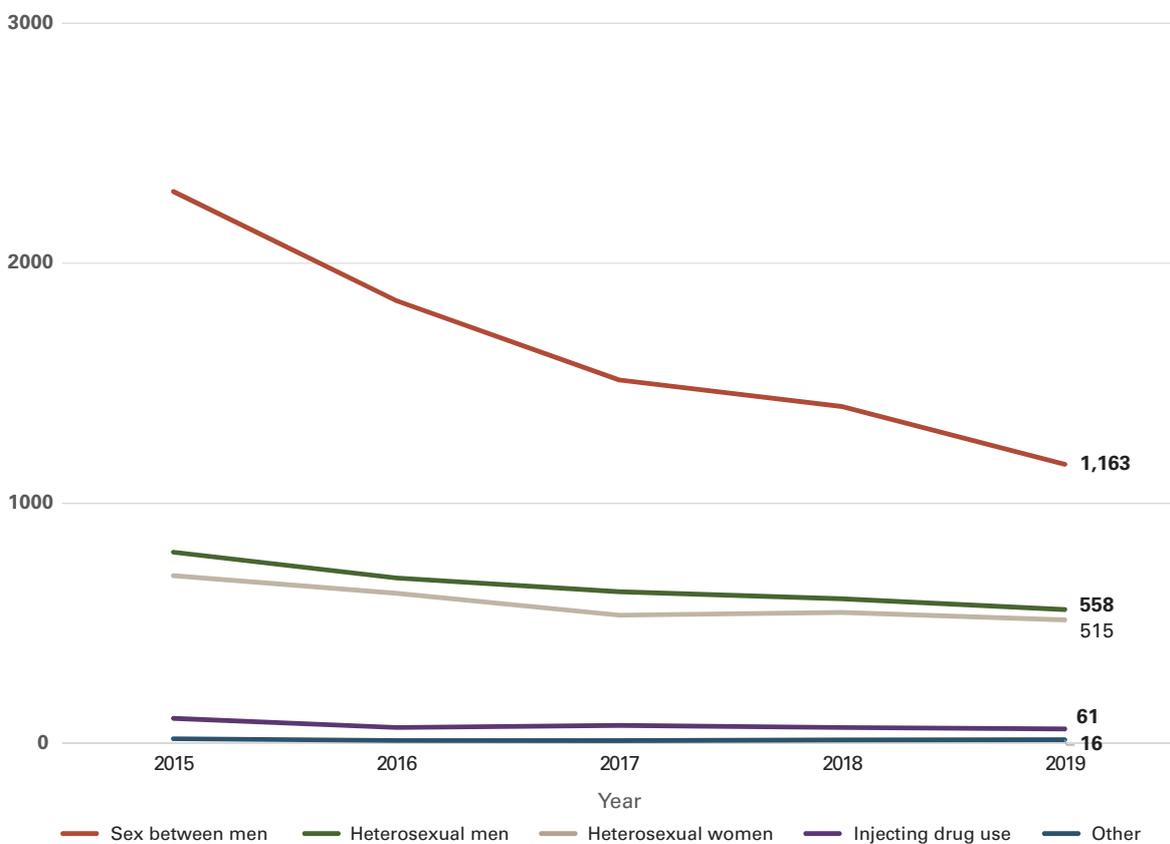
Ethnicity of people accessing care in England



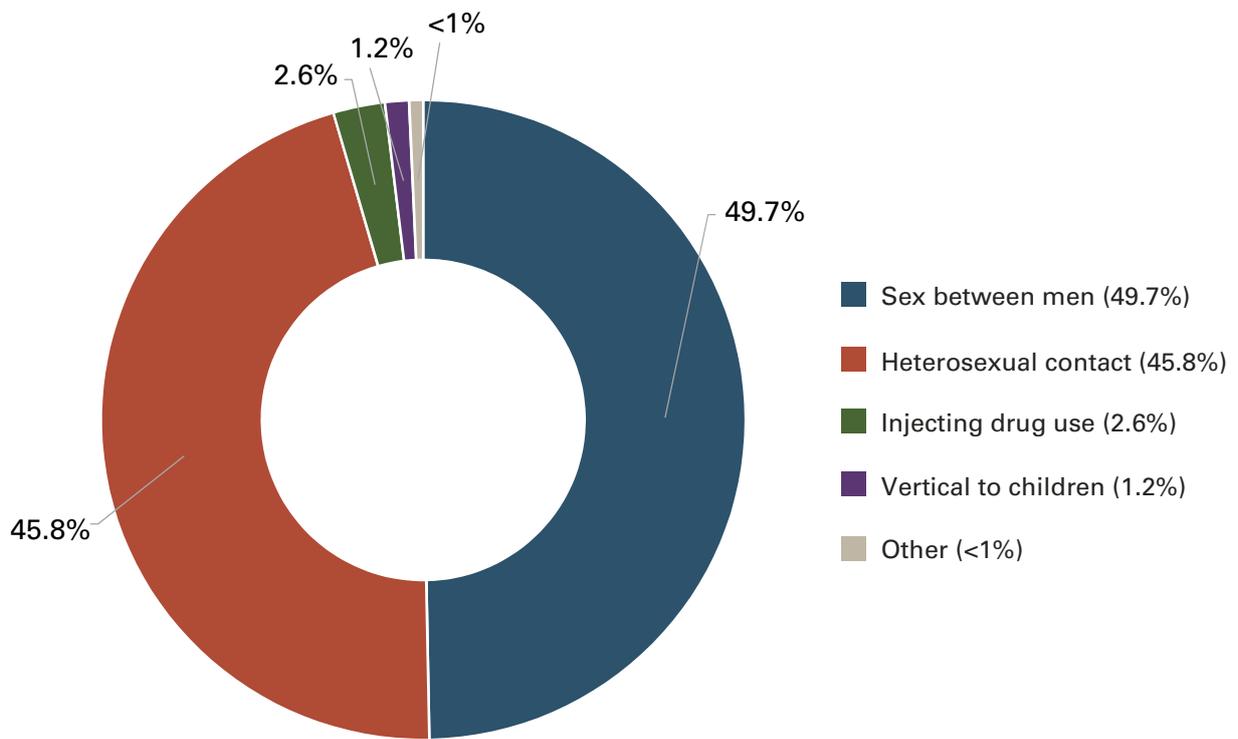
Age of people accessing care in England



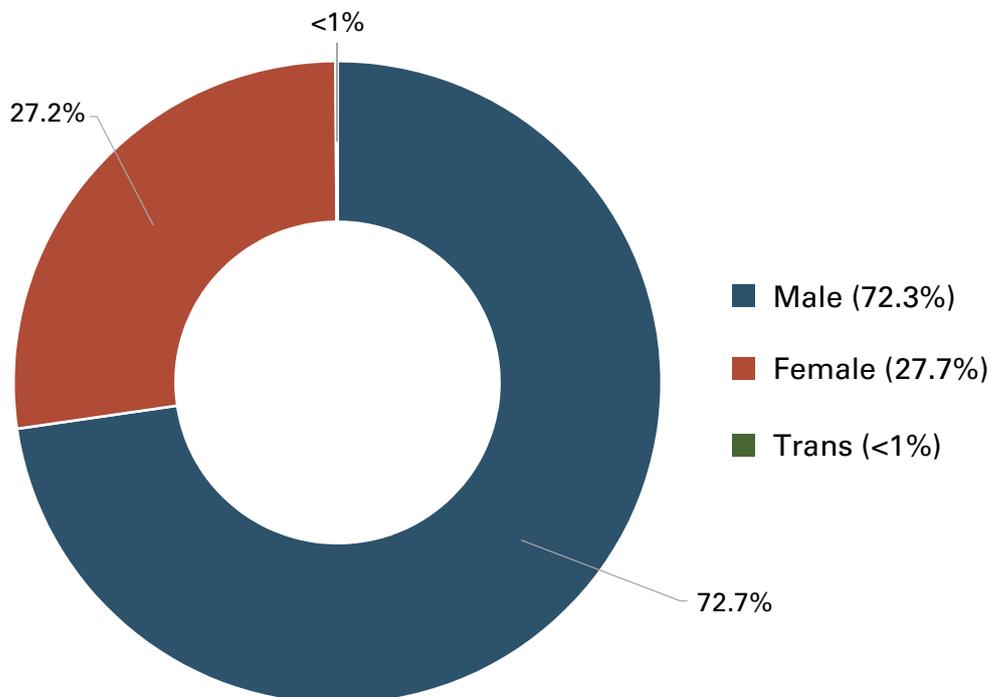
Transmission route of people accessing HIV care in England



Trends in new diagnosis in England



Transmission route for newly diagnosed in 2019



Gender of those newly diagnosed in 2019



OUR TARGETS

We believe time-bound targets will drive progress and ensure accountability on common goals. This has served England well – with the UNAIDS ‘90-90-90 target’ met early.

To end new transmissions, we require measurable targets that provide concrete milestones towards our end goal. We believe both existing and new time-bound targets will drive progress and ensure accountability.

Decreasing HIV transmission targets should be applied to each key population in England – this is the only way progress will be equal across population groups. Success should be measured and reported by government to parliament alongside official HIV statistics every year. The ambitious target to reach an 80% reduction by 2025 is new and essential, as we know that the last transmissions will be the hardest to find and will require additional focus. To keep the country’s focus, the government must commit to England being the first nation in the world to end new HIV transmissions by 2030.

Targets	At a population level, these targets will see the following impact in numbers of new HIV transmissions:			
	New diagnoses (first diagnosed in the UK) in England	2019*	By 2025	By 2030
By 2025: Reduce new HIV transmissions by 80%		2,861	Under 600	Under 100
By 2030: End new HIV transmissions	Gay and bisexual men	1,163	< 250	< 50
	Heterosexual women	558	< 120	< 25
	Heterosexual men	515	< 100	< 19
	Black Africans	466	< 100	< 18
	Deaths in England	472	Under 95	Under 11
England: the first country to end new HIV transmissions	AIDS at HIV diagnoses	219	< 45	< 5
*Based on data from Public Health England, 2020				

There has historically been no consensus definition of ending new HIV transmissions in England, as defining it is not easy. UNAIDS suggests an ‘elimination’ definition of less than one new infection per 10,000 per year. We heard during our evidence gathering process that the word ‘elimination’ can imply that we don’t want people living with HIV to lead healthy, long lives. Therefore, we have not used the word ‘elimination’ in this report.

England has already reached this level for the overall population. However, within key population groups and in some places around the country, the level of infection per 10,000 in the population is a lot higher. Therefore, our targets seek to define our goal in a meaningful and measurable way for relevant sub populations.

There are also still significant numbers of new HIV transmissions, many living with undiagnosed and untreated HIV and far too many deaths in 2020 in England related to untreated HIV – these are all areas where further progress is possible.

In the UK data is collected on how many people were newly diagnosed with HIV in each year. These newly diagnosed people may have acquired HIV recently, or some time ago. Those people who have been living with HIV for some time are described as a ‘late diagnosis’ – this is problematic because the person is likely to become ill and have much greater health concerns and a higher risk of death. They also remain infectious and able to pass HIV on. The UK also uses a range of methods to also estimate HIV incidence – the number of people who acquire HIV in each year.

In order to know we are making progress, we need to know that with the same or increased numbers of HIV tests, both the diagnoses and incidence rates decline. By reducing diagnoses whilst testing the same number we know that we are finding those living with HIV and able to pass it on. By reducing the incidence level we know that the actual number of people acquiring HIV each year is reducing.

The Commission has set targets, which we believe are essential for motivating and evaluating efforts to scale up and sustain prevention efforts until ‘transmission has ended’. We believe that targets measuring the number of new diagnoses first diagnosed in the UK will be the most effective measure – these figures breakdown by both nation and by important sub-demographics. It is important that the reductions projected for gay and bisexual men are mirrored across all groups. Concurrently, it will also be important to see the incidence level continue to reduce – demonstrating that this approach is successful.

HIV is a global issue and one which does not respect geographic borders. In England, 53% of HIV diagnoses made in 2019 were among people born abroad. The most common regions of birth for migrants newly diagnosed with HIV in England in 2019 were Europe (ex-UK) (16%), Africa (10%), Eastern Africa (9%), Asia (8%). There is also a significant cohort of people born in the UK who acquired HIV whilst travelling or living abroad. In 2019, they represented 15% of new infections in people born in the UK, with this group more likely to have acquired HIV through heterosexual contact.

The term ‘health tourism’ has been used by some politicians and in the media to imply that some people come to the UK to benefit from free healthcare at cost to taxpayers. No evidence to support this claim was found or reported to the HIV Commission. Instead, we received reports that charging for other aspects of healthcare and the sharing of data between the NHS and immigration enforcement often deters migrants from seeking the care they are entitled to, even though HIV care is universally free. Meanwhile, in 2018, short-term visitors to the UK receiving ART (a form of treatment for people living with HIV) accounted for only around 1.2% (about 100) of those accessing HIV services.

We believe that universal access to testing, care and treatment is the cornerstone of HIV prevention in the UK. As Commissioners, we have identified many things that need to change to meet our ambitious targets, but none of this will work without maintaining universal access to HIV treatment and ensuring that this is widely promoted. This foundation is essential, but we have a long way to go to ensure that everyone is aware of this right to HIV care and is supported to access these services.

OUR RECOMMENDATIONS

'Ending HIV transmissions in England by 2030' is not just a government target but has the potential to change lives for many. At the moment nearly 3,000 people a year are newly diagnosed. Achieving this goal will prevent tens of thousands of new infections and all the complications that can follow – mental health challenges, medical complications, living with stigma and discrimination. This is such a worthwhile aspiration, it requires urgent government action.

To meet the ambition to end new HIV transmissions in England by 2030, the government should reaffirm this target, but also adopt the new interim milestone recommended by this commission to see an 80% reduction by 2025. This will ensure we are on track. We should seek to build on positive progress made to date and ensure that the government commit to England being the first country to achieve a goal that will change so many lives.

“The government should reaffirm [its 2030] target, adopt the new interim milestone recommended by this commission to see an 80% reduction by 2025 ... and ensure that the government commit to England being the first country to achieve a goal that will change so many lives.”

The worryingly high number of late HIV diagnoses is bad for patients, results in more progressed disease, leads to new preventable transmissions and impacts public finances. Every late diagnosis must be viewed as a serious incident requiring investigation, lessons being learned and a report produced to drive change in local health systems.

From the evidence received by this commission, it is clear that the single most important intervention to meet the 2025 and 2030 goals is widespread HIV testing, made routine across the NHS and delivered as opt-out – not opt-in – provision. The fragmentation of the system makes this more challenging, but no less important.

The health system must, over the next decade, make every contact count. Every blood test undertaken that is not also used as a chance to test for undiagnosed HIV, is an opportunity missed. No longer should people leave a sexual health clinic without being offered an HIV test. But to achieve this ambitious goal our attention must be wider, with a whole health system approach to testing. People presenting at A&E, registering for a GP and accessing other health services should be tested for HIV, with the default approach being an opt-out – not opt-in – for an HIV test. The success of this approach in maternity services shows us what is possible and how impactful it can be. Changes in HIV testing are urgent and national funding to enable this is key.

Finally, in a system so fragmented, leadership is necessary and accountability crucial. This is a role only national government can take on – the more it does the more our success is assured.

- 1** England should take the necessary steps to be the first country to end new HIV transmissions, by 2030, with an 80% reduction by 2025. Jointly the Department of Health and Social Care and the Cabinet Office should report to parliament on an annual basis the progress toward these three goals.
- 2** National government must drive and be accountable for reaching this goal through publishing a comprehensive national HIV Action Plan in 2021.
- 3** HIV testing must become routine – opt-out, not opt-in, across the health service.

The success in ending HIV transmissions lies in tackling HIV-related stigma and health inequalities. The building blocks of this report – and any future HIV Action Plan – are service transformation, equity for HIV affected communities, increased resources, bold leadership and effective partnerships. The report addresses each of these and sets out actions and calls for change.

Address stigma and health inequalities

Transformation	Equity	Resources	Leadership	Partnerships
Build a health and care system which can take advantage of innovation.	Address social and structural barriers to HIV testing and treatment access.	Ensure there are the right resources to meet the 2025 and 2030 goals.	Make HIV a national and local priority, and set a desire for England to be the first country to end new transmissions.	Strengthen alliances within and beyond the HIV community.

STIGMA AND HEALTH INEQUALITIES

Stigma and health inequalities create significant barriers to accessing testing, prevention, and care. This has become more acute since COVID-19 and without action, we risk progress slipping further. Everyone involved in the health and social care sector has a responsibility to stop HIV stigma and address health inequalities throughout their work.

There is an urgent need to end stigma and discrimination against people living with HIV. This will not be a simple process and requires that the law and government policy properly protect against discrimination and does not perpetuate stigma. This must be done while changing public attitudes in order to end stigma.³ Submissions received emphasised that better knowledge about HIV can help to challenge associations of HIV with contagion and death but cannot alone eradicate HIV stigma. Stigma remains deeply bound up in other discriminations, with racism, xenophobia, transphobia, sexism and homophobia all playing key roles in continued stigma and misconceptions about people who live with HIV.

This hampers attempts to get people to come forward for testing and means too often those living with HIV are diagnosed late and risk complications. It stops dialogue about HIV in families, health settings and communities that could otherwise educate people about the modern realities of HIV and its treatment options. With the right medication, HIV is life changing not life threatening – this is often poorly understood among healthcare professionals and the public alike. Despite the fact that people living with HIV are protected by the Equality Act 2010, people living with HIV face discrimination in employment, access to services and often in their personal lives.

“Addressing stigma is not just ‘zero stigma’ as this definition only depicts something we don’t want. Zero stigma may mean that people with HIV are just tolerated rather than fully accepted, respected, and included.”

Positively UK

The COVID-19 crisis has held up a mirror to a reality that the HIV sector has long known: that structural inequalities have serious implications for public health. From its beginning, the HIV epidemic has represented an acute health inequality, affecting some key populations vastly disproportionately. In addition, recent declines in estimated HIV transmissions have not been spread equally amongst all key population groups or across regions.⁴ For example, while the most significant drop has been amongst white gay and bisexual men living in London, aged 25 to 49, increasing numbers of gay and bisexual men born abroad are more likely to be diagnosed with HIV than those born in the UK.⁵

That structural inequalities influence health outcomes is well evidenced. The 2010 Marmot Review into health inequalities in England found that the lower someone’s social and economic status, the poorer their health is likely to be.⁶ The review exposed that people living in poorer areas in

³UNAIDS, *Fast Track: Ending the AIDS Epidemic by 2030*, 2014.

⁴Public Health England, *HIV in the United Kingdom: Towards Zero HIV transmissions by 2030*, 2019

⁵Public Health England, *HIV in the United Kingdom: Towards Zero HIV transmissions by 2030*, 2019.

⁶Michael Marmot, Fair Society, Health Lives: The Marmot Review, 2010.

England will die seven years earlier than people living in the richest neighbourhoods and will spend more of their lives with a disability. The review also confirmed that health inequalities are preventable and reiterated the economic case for prevention rather than treatment. Marmot also argued that action on these inequalities not only requires action on health, but on determinants of health: education, occupation, income, home and community. Returning to these findings 10 years later, Marmot found that life expectancy had fallen for women in the most deprived communities outside London, and in some regions also for men. The rate of slowdown has been the greatest in England for 120 years. The findings of these reviews were warnings for what was to come.⁷

COVID-19 has further increased many of these health inequalities. In June 2020, a UNAIDS report noted the effects of COVID-19 on the HIV response as three-fold: there has been a shift in the attention of healthcare systems towards COVID-19, the health challenges of people living with HIV have been exacerbated and system level weakness in the epidemic response has been highlighted.⁸ COVID-19 has disproportionately affected many of the marginalised groups most affected by HIV. Particularly, data published by Public Health England in June 2020 showed that BAME communities in particular were more likely to die of COVID-19.^{9 10} A key theme highlighted by this work on COVID-19 is also true of the HIV response: action on inequalities must be data led. If our data is not robust, it holds back the progress that can be made in addressing inequalities. Solving these structural inequalities goes beyond HIV and is not only the work of this commission, but it is nonetheless vital that tackling them underpins every part of our work.

Stigma, discrimination and health inequalities hold back our efforts to end new HIV transmissions at every stage. All policies and future practice should be assessed to determine whether they do not further stigmatise HIV diagnosis, perpetuate discrimination and exacerbate health inequalities.



ACTION 1

All national and local HIV treatment and prevention initiatives should explicitly plan and evaluate how they will address HIV-related stigma, discrimination and health inequalities.

Alongside this, we must increase the knowledge and awareness of HIV amongst the general healthcare workforce. Too often we heard accounts of stigma experienced within the healthcare system, including nurses 'double-gloving' and multiple accounts of appointments being moved to the end of the day so rooms could be 'decontaminated'. This exposes a serious problem in the level of knowledge among some healthcare staff who don't know or believe that a person with an undetectable viral load cannot transmit HIV – this is known as undetectable = untransmittable or U=U. This perpetuates stigma and leaves people living with HIV deterred from engaging with care. Not only this, but it is symptomatic of other problems: that many healthcare staff are not aware of indicators of HIV and believe that it only affects certain minority groups. This can lead to patients being seriously ill before they are tested for HIV.

⁷Michael Marmot, *Health Equity in England: The Marmot Review 10 years on*, 2020.

⁸UNAIDS, *Seizing the Moment: Tackling entrenched inequalities to end epidemics*, 2020.

⁹Public Health England, *Disparities in the Risks and Outcomes of COVID-19*, May 2020.

¹⁰Public Health England, *Beyond the Data: Understanding the impact of COVID-19 on BAME Groups*, 2020.

“Patients often report trauma as a result of needing ICU care before HIV testing is considered. Further trauma is reported on diagnosis when they are left bewildered and unsupported by staff who are unaware of new treatments and services available and may be insensitive to the confidentiality requirements of newly diagnosed HIV+ patients.”

Mary

People living with HIV often experience stigma within the healthcare system itself, which acts as a barrier to people living with HIV accessing services. This stigma also indicates that not all of the health and social care workforce has sufficient up-to-date knowledge of HIV, which can also mean that HIV indicator conditions go unnoticed.



ACTION 2

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

Public awareness campaigns

England has a long history of using social marketing campaigns to increase knowledge and awareness of HIV. From the 1986 “Don’t Die of Ignorance” campaign to recent efforts targeting most at-risk populations, such as Black African communities and gay and bisexual men. In England, the commissioning of campaigns has been carried out by multiple sectors and has proved to be effective at increasing and normalising HIV testing and condom use, reducing HIV stigma and providing the latest up-to-date information on HIV. The return of investment on campaigns can be variable among populations and there is always a risk of enhancing stigma among communities if campaigns are generally targeted, rather than more carefully tailored towards communities. Campaigns which increase fear and stigma in their messaging are counterproductive in encouraging people to test and talk about HIV, impacting the quality of life for people living with HIV. Instead, campaigns must be tailored to communities in a way which informs and supports, without isolating specific populations.

At evidence hearings, we heard that there is a tension in current campaign messages. On the one hand, we encourage people to access prevention so as not to acquire HIV, while also highlighting that improved treatment means HIV need not affect your life and health but does reduce radically – potentially to zero – someone’s ability to pass on the virus. Both are relevant messages, which need to be carefully propagated to ensure they complement each other as part of a combination HIV prevention strategy. Effective campaigns require simple messages, and we know combination HIV prevention can be inherently complex to explain.

Campaigns have been one of the places where we have seen successful early development and adaptation of new technologies. The use of digital approaches in social marketing has dramatically changed the way campaigns are formulated. They are now able to 'hyper target' communities with different messaging becoming an invaluable tool to influence and impact population health at scale.



Health Equity Considerations

- Campaigns tailored to particular communities must include those communities at all stages and all levels.



Stigma Considerations

- Working with people living with HIV and key populations is essential to ensure promotion activities are not inadvertently stigmatising.

Treatment as prevention and U=U

The discovery¹¹ that people living with HIV who have an undetectable viral load cannot pass HIV on through sexual transmission was a game-changer in the fight against HIV. In 2015, NHS England introduced a policy known as 'Treatment as Prevention' which enabled doctors to prescribe HIV medication to people living with HIV before it was otherwise clinically indicated, to prevent onward transmission.¹² Evidence from the START Trial then demonstrated that those who begin HIV medication as soon as possible after diagnosis have better health outcomes – which further changed prescribing practice in England.

This understanding is known internationally as undetectable = untransmittable or U=U.

In the UK, 89% of people living with HIV have an undetectable viral load. Of those receiving treatment, 97% have an undetectable viral load. U=U makes the reasons for providing good treatment two-fold: it enables people living with HIV to lead healthy lives and means that they cannot pass on HIV.

The U=U message is widely shared by HIV activists internationally, including through Terrence Higgins Trust's very successful 'Can't Pass It On' campaign. It enhances motivation for adherence to antiretrovirals, mitigates anxieties around HIV testing and challenges some instances of stigma that relate to fear of transmission. U=U also assures people with HIV that they can conceive naturally, without risk to their infant and have sex without fear of passing on the virus to their partner. Anecdotal evidence suggests that the message is broadly welcomed by people living with HIV and there is some community frustration that the wider public are not better informed on this significant progress. Although there have been small incremental changes in public understanding of U=U, recognition of the message remains low.

¹¹RW Eisinger, CW Dieffenback, AS Fauci, *HIV viral load and transmissibility of HIV infection: undetectable equals untransmittable* *Journal of American Medical Association*, 2019.

¹²<https://www.england.nhs.uk/commissioning/wp-content/uploads/sites/12/2015/10/f03pc-tasp-oct15.pdf>

U=U messaging refers to sexual transmission. The evidence for the U=U messaging on breastfeeding and other exposure routes (including sharing needles) is still evolving. A roadmap for global collaborative research exists in order to enable those who want to breastfeed to make a fully informed decision.¹³



Health Equity Considerations

- Engagement with and understanding of the U=U message may vary by demographic group so greater effort and resources may be required to reach all communities equitably.



Stigma Considerations

- Some who adhere to treatment still cannot reach an undetectable viral load. It is important that the U=U message is widely understood and celebrated, but this should not be at the expense of increased stigma of those whose viral load is detectable.
- At the moment, U=U is not understood or believed by enough healthcare professionals, let alone the general population. Only 21% of people believe that viral suppression means that someone can't pass it on.¹⁴

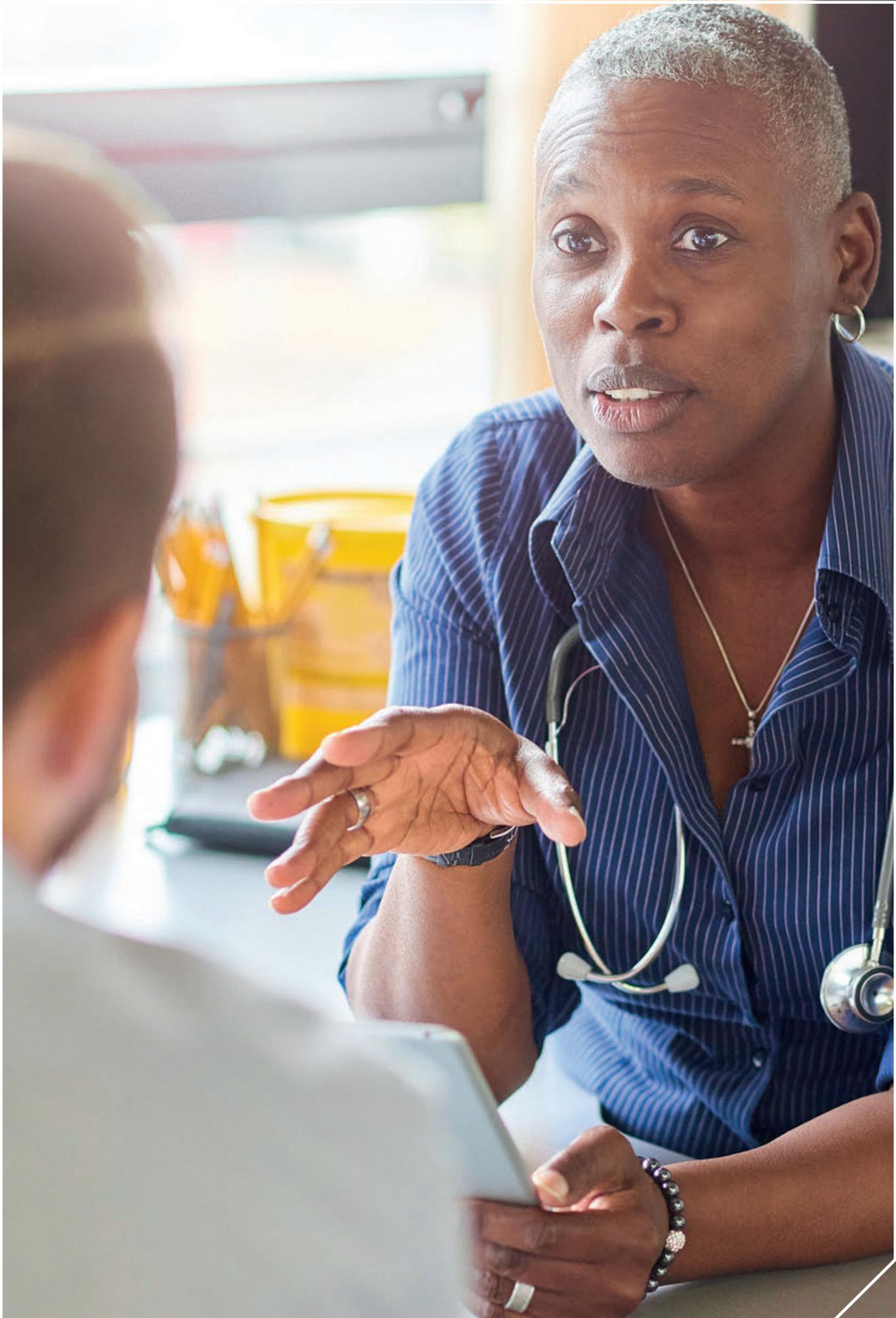


ACTION 3

Implement a programme of coordinated national campaigns across the decade, aiming to enable residents in England to know how to find out their HIV status and increase their awareness of combination HIV prevention.

¹³Waite C et al. Does U=U for breastfeeding mothers and infants? Breastfeeding by mothers on effective treatment for HIV infection in high-income settings. Lancet HIV. doi:10.1016/S2352-3018(18)30098-5(27 June 2018). [https://www.thelancet.com/journals/lanhiv/article/PIIS2352-3018\(18\)30098-5/fulltext](https://www.thelancet.com/journals/lanhiv/article/PIIS2352-3018(18)30098-5/fulltext)

¹⁴Terrence Higgins Trust / You Gov poll, 2019



TRANSFORMATION

Build a health and HIV care system which can take advantage of innovation.

Progress in HIV prevention and treatment has not been consistent across the last four decades. It has occurred in stages, with 'disruptive innovations' causing leaps in improvements.¹⁵ The early days of treatment, the discovery that U=U (that people with an undetectable load "can't pass it on") and PrEP (the HIV prevention drug, pre-exposure prophylaxis) have been game-changers in our response to the epidemic, and have together contributed to the lower rates of new transmissions in recent years, and the gains we've seen. It is important that the health system is able to take advantage of these and future innovations quickly and effectively.

The COVID-19 epidemic will change HIV treatment. As all of us moved to life restricted to our homes, practitioners across the continuum of HIV prevention and care innovated at unprecedented speed to move services online as much as possible. Although small steps towards increasing digitalisation were already underway, this time change happened fast as many parts of prevention and treatment went virtual for the first time. No one really knows what the lasting consequences of COVID-19 will be for our society, but we can say with certainty that we will not be returning to the old normal.

HIV testing

Free and confidential HIV testing is available for everyone, regardless of immigration or residency status, through open access sexual health services (SHS). Guidance also recommends free testing in a variety of other settings including, primary care, secondary care, prisons, community settings and online. In reality, however, implementation of guidance is patchy and testing is not routine or universally accessible to all. There are some paid for testing services, online or through pharmacies (such as HIV self-tests), but these are restricted to those who know about and can afford them. HIV testing informs people of their HIV status – enabling people living with HIV access to treatment and stopping onward transmission.

Accountability for delivery of HIV testing, and who pays for it, is another victim of the fragmented healthcare system in England and the split between primary care and public health commissioning. Solving this problem is a priority so we can find everyone living with HIV, ensure they have access to the lifesaving care they need and deserve, and end new transmissions by 2030. It is the single most important change needed to meet this goal.

Everyone should know their HIV status. This will require a significant upscale in HIV testing opportunities across online, community and healthcare settings. It must become a routine and expected part of every person's interaction with the healthcare system, with inclusion of HIV in blood screens being normalised. The increased opportunities for testing for other blood borne viruses (BBVs) would be an additional benefit of this change.

¹⁵Jeffrey Crowley and Christian Ramers, 'Disruptive Innovations to Help End the HIV Epidemic and The Rise of Telehealth', AIDS2020 Conference.

Opt-out HIV testing in antenatal services

There is one real success story in NHS HIV testing. Maternity services have mainstreamed HIV testing and deliver the service in a non-judgemental environment with remarkable results. Opt-out testing for HIV is routine for pregnant women and there is now a 99% testing coverage. This has been an incredibly effective way of diagnosing women living with HIV of reproductive age who may not otherwise have tested. Women who are diagnosed during pregnancy can start treatment, improving their health outcomes and preventing vertical transmission (the rate is now less than 0.5% in the UK). However, antenatal testing alone does not reach all women and other initiatives have so far been woefully inadequate at reaching women.

Despite various initiatives, elsewhere the picture is not one of routine or mainstream testing.

HIV testing in sexual health services (SHS)

In 2019, overall HIV testing coverage was only 65% in specialist sexual health services, which are the foundation of any HIV testing strategy. While this represents a continued increase in HIV testing in this environment, this has been largely driven by increased testing of gay and bisexual men (GBM). We can and must do much better.

Of the 549,849 people not tested for HIV in a specialist sexual health service last year, 46% were not offered a test and the remainder declined testing. This means over a quarter of a million people who accessed a sexual health service were not even offered a test. These were overwhelmingly women, and disproportionately women of colour. This is also reflected in those who declined a test. Heterosexual women were more likely than heterosexual men to decline a test (25% vs 13%) and, according to Public Health England, “few GBM declined testing (4%), in contrast to 20% of Black African heterosexual women and 9% of Black African heterosexual men.”¹⁶

In 2008, the British Association for Sexual Health and HIV (BASHH), British HIV Association (BHIVA) and the British Infection Association (BIA) developed national testing guidelines that recommend universal HIV testing in sexual health services and promote the normalisation of routine HIV testing. It is the view of this commission that the BASHH, BHIVA and BIA guidance must be implemented with haste. No one should leave a sexual health clinic without being offered an HIV test and up-take should be dramatically increased so that refusal is an exceptional event.

HIV testing in other healthcare settings

National Institute for Health and Care Excellence (NICE) guidance on increasing testing uptake (2016), recommends testing in a broad range of settings. In areas of high or extremely high local HIV prevalence (more than 2 per 1000 in the population and 5 per 1000 respectively), NICE calls for testing on registration in primary care and in secondary and emergency care (hospitals and A&E) to everyone who is undergoing blood tests for another reason. BASHH, BHIVA and BIA guidelines further support this, recommending that testing is opt-out and routine in many parts of the NHS.

¹⁶Public Health England, Trends in HIV testing, new diagnoses and people receiving HIV-related care in the United Kingdom: data to the end of December 2019. October 2020 https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/931964/hpr2020_hiv19.pdf

“Providing HIV testing to all patients attending the emergency department, regardless of social group (gender identity, ethnicity, religion or sexuality) in areas of high prevalence has a significant role in reducing the stigma associated with testing and the potential diagnosis of HIV.”

Guys and St Thomas’ NHS Foundation Trust

At evidence hearings across the country, we were told time and time again by stakeholders that the NICE guidelines for testing provided a good framework for testing strategies but were not being followed. Urgent implementation of these guidelines, not just in hospitals and A&E departments, but also GP surgeries, is needed.

As we heard in our evidence sessions, one of the major barriers is funding, both in terms of clarifying responsibility and accountability, and in terms of making the necessary investment available.

Who pays? The clinical or public health commissioners? This confusion has gone on too long and has led to a hotchpotch of initiatives and models in different areas with mixed success and poor coordination and integration across services.

As well as the pressure on the limited public health grant, economies of scale don’t support localised routine testing. As we make progress towards our goal of ending HIV transmissions the number of people we need to test compared with the diagnoses made will inevitably increase. If we are doing our job right, the positivity rate of testing will decrease, along with overall incidence of HIV. This is not a reason to slow testing down, as returns on investment appear smaller, but to double-down efforts. The upscale in testing that is needed cannot be simply absorbed to local-level responsibilities and budgets. Only action from the Department of Health and Social Care can solve this problem.

PHE data indicated that local initiatives have led to an increase in testing in some A&E departments. As a result of this increase in testing volume, the positivity rate decreased from 1.3% to 0.6%.¹⁷ But positivity rates are still higher in A&E than in most settings. A&E HIV testing has again been boosted by the fact many trusts included HIV testing in their A&E COVID-19 testing protocols – a welcome development. However, there is a real concern that without further incentive and national policy direction, this will not be sustained.

It is the view of this commission that it will need more than clarity about commissioning responsibilities, there needs to be new funding made available both for existing bodies involved in testing, as well as a national HIV testing programme that will drive this agenda forward and coordinate implementation with those involved in delivery of testing locally and nationally.

¹⁷PHE ‘HIV in the United Kingdom: Towards Zero HIV transmissions by 2030’ (2019)

Improving access to testing: evidence from Lambeth, Southwark and Lewisham

The Elton John AIDS Foundation's Social Impact Bond (SIB) funds HIV testing in the London boroughs of Lambeth, Southwark and Lewisham, with opt-out testing in A&Es, regular testing in GPs practices, and targeted testing by community groups. The three-year programme takes an outcomes-based approach and aims to increase HIV diagnoses and engagement into care. This is done in partnership with local NHS bodies and the three councils with some of the highest UK HIV incidences. The whole project is supported by funding from The National Lottery Community Fund and the London Borough of Lambeth.

In 2018 there were an estimated 1,000 people unaware they had HIV in Lambeth, Southwark and Lewisham.¹⁸ Over 140,000 HIV tests have been delivered on an opt-out basis in A&E departments through the SIB, changing the conversation from 'do you want a HIV test' to 'we routinely test unless you ask us not to' and thus vastly increasing the acceptability of HIV testing to patients. Consequently, from October 2018 to September 2020, 130 people were newly diagnosed with HIV and started treatment. A further 107 returned to HIV care after a substantial break in treatment – an important outcome helping this group reduce their viral load so they 'can't pass it on' and have improved health personally.

The SIB's activities highlight the importance and effectiveness of: one, opt-out HIV testing in emergency departments; two, regular testing by GP practices offered whenever blood is taken or at new registration; three, community organisations acting as a bridge to engage vulnerable people in HIV testing; and, four, dedicated audit and recall systems to re-engage people disconnected from HIV care.

These interventions improve the health of people living with HIV, reduce future HIV transmission, and generate cost savings for the public purse. Finally, initial modelling on the SIB programme shows that these testing and engagement interventions create significant savings to the NHS from two sources – reduction in lifetime costs of care for people living with HIV through earlier engagement in treatment, and avoidance of future transmission and the lifetime care costs that each new patient incurs.

The Elton John AIDS Foundation conducted an analysis of healthcare costs avoided through the SIB in November 2020, using lifetime costs of treatment for people with HIV, likelihood of HIV transmission, and likely number of sexual partners each year. They estimated that over £220,000 in future healthcare costs is saved per person who was diagnosed and linked into the right treatment care. That's because it saves the cost of intensive inpatient medical care associated with very late HIV diagnosis and limits the possibility of further transmissions. This suggests that, by linking 256 people into care between November 2018 to November 2020, future healthcare costs of £56,800,000 have been avoided. Implementation costs to the SIB providers have been approx. £1,500,000 over that period, which implies a net 'healthcare costs avoided' total of over £55,000,000.

Expanding the scope of routine HIV testing

The evidence from the SIB underpins why HIV testing must be increased in A&Es and primary care across all areas with high or extremely high incidence of HIV as soon as possible. But this will not be enough to end new transmissions completely and we need also to look beyond areas of high and extremely high prevalence to reach everyone. Cost savings will be less in areas of lower incidence due to the higher level and costs of testing required to reach each undiagnosed

¹⁸Lambeth Southwark and Lewisham (LSL) sexual reproductive health and HIV 2019-24 Strategy, March 2019: <https://www.lambeth.gov.uk/adult-social-care-and-health/your-health/sexual-health-and-hiv/sexual-and-reproductive-health>

person living with HIV. Again, this is not a reason not to do it. A national approach to investment and coordination could support routine HIV testing at this scale and expand it beyond (but including) areas with the highest prevalence.

A national testing programme should also prioritise the exploring and enabling of testing in non-mainstream services that are more likely to be accessed by those who face broader inequalities and marginalisation. This should include termination clinics, as per NICE guidelines 2016, while doing cervical screening and at gender clinics.

Pharmacies are an ideal intermediate location, especially in towns and rural areas, where other services are not nearby or home sampling/testing is not desirable. There is currently no charge backs agreed for pharmacies when doing HIV testing[RA2], and this needs to change.

All of these services are potential opportunities to make PrEP available to those less likely to have access to sexual health services or unaware of PrEP availability and its benefits. To be able to provide PrEP, HIV testing needs to be available in all these settings.

The Testing Traffic Light

Below are examples of some healthcare services where the HIV Commission believes HIV testing should be provided. Green indicates that normalised HIV testing is policy and practice, currently in antenatal screening; amber indicates where there is direction to test but application is not thorough nor routine; red indicates areas for HIV testing to take place to meet the 2025 target for 80% reduction in new transmissions, the 2030 goal to end HIV transmissions and the aim for England to be the first country to eliminate HIV transmissions by 2030. This improved testing situation would be necessary to make PrEP available to all groups.

Service	Current policy and guidance	Responsibility	Implementation	To reach 2030 goal
Maternity services / antenatal screening	Offered to all women on opt-out basis as part of the Infectious diseases in pregnancy screening (IDPS) programme.	Funded nationally by NHS England through Section 7A agreement.	99% testing coverage. Transformative results, almost eliminating vertical transmission and dramatically increasing the proportion of women diagnosed.	Continue current practice. Identify factors in success and learning for increasing uptake elsewhere.
Sexual health services (SHS)	NICE 2016 guidance- all should be offered on attendance. BASHH, BHIVA and BIA guidelines 2020 – universal testing on an opt-out basis.	Local authorities through devolved public health grant.	In 2019, only 65% testing coverage across SHS attendees. Almost half (43%) of those not tested were not offered a test.	Implementation of opt-out HIV testing to all SHS attendees.

Prisons	NICE guidance on HIV testing and physical health of people in prison, both 2016 – all people should be offered an HIV test on an opt-out basis.	Joint commitment by NHS England, add National Offender Management Service (NOMS) and PHE through their Partnership Agreement on healthcare in prisons.	Mixed implementation. In 2018 77% were offered a test with only 44% uptake. Testing practice is unlikely to be truly opt-out when it is in place. Test positivity rates are higher than other settings (1.2%).	Renewed efforts to implement true opt-out testing for people entering prison in England.
A&Es in areas of high or extremely high local HIV prevalence	NICE Guidance 2016 – all should be offered on admission and in routine blood tests. BASHH, BHIVA and BIA 2020 guidance – all patients accessing should be offered a test and recommends an opt-out approach.	Unclear responsibility with some local authorities funding through the public health grant. Some STPs/ ICSs have implemented across admissions during COVID-19.	Not routinely implemented across the country. Difficult to collect data on testing in this setting due to differential data collection/reporting mechanisms. Challenges around both funding and implementation at a local level.	Implement opt-out HIV testing for all emergency and secondary care admissions and/or when bloods taken, starting in high and extremely high prevalence areas.
Hospitals in areas of high or extremely high local HIV prevalence	BASHH, BHIVA and BIA 2020 guidance – testing should be done in secondary care when clinically indicated.	CCG funded when clinically indicated.		All people presenting with HIV indicator conditions should be offered an HIV test.

<p>GP surgeries in areas of high or extremely high local HIV prevalence</p>	<p>2016 NICE guidelines – all should be offered a test on admission.</p> <p>BASHH, BHIVA and BIA 2020 guidance – all patients accessing should be offered a test and recommends an opt-out approach.</p> <p>BASHH, BHIVA and BIA 2020 guidance – testing should be done when clinically indicated.</p>	<p>Unclear responsibility – Some local initiatives funded through the local authority public health grant.</p> <p>Funded by Social Impact Bond in Lambeth, Southwark and Lewisham.</p> <p>CCG funded when clinically indicated.</p>	<p>Poor implementation though has been done on an ad hoc basis. Difficult to collect data on testing in this setting due to differential data collection/reporting mechanisms.</p> <p>Key to increasing testing to those less likely to access an STI clinic – women, Black communities and other ethnic minorities and those living outside cities and big towns.</p> <p>Challenges around funding responsibility and nervousness amongst GPs around offering HIV tests have been barriers.</p>	<p>Implement opt-out testing for all new registrants at GP surgeries.</p> <p>All people presenting with HIV indicator conditions should be offered an HIV test.</p>
<p>During cervical screening</p>			<p>No current guidance but is an opportunity to reach women living with HIV who have not been pregnant or acquired HIV post-pregnancy.</p>	<p>Offered to women and people with a cervix as part of the service.</p>
<p>A&E in areas of low or medium local HIV prevalence</p>	<p>NICE guidance 2016 – recommends testing on admission for key populations, those reporting possible risk or when clinically indicated.</p>	<p>Unclear responsibility.</p> <p>CCG funded when clinically indicated.</p>	<p>Not routine. High levels of late diagnosis (common in lower prevalence areas) and look back data indicate that people are also being missed who present with indicator conditions.</p>	<p>HIV testing should be routine on an opt-out basis for anyone receiving a blood test and on admission.</p>
<p>Hospitals in areas of low or medium local HIV prevalence</p>			<p>Difficult to collect data on testing in this setting due to differential data collection/reporting mechanisms.</p>	<p>All people presenting with HIV indicator conditions should be offered an HIV test.</p>

<p>Pharmacies</p>	<p>NICE guidance 2016 – recommends community testing in pharmacies in areas of high or extremely high prevalence.</p> <p>No system of charge back for the pharmacist to undertake this work.</p>		<p>Sometimes available to purchase in pharmacies.</p> <p>An intermediate location for those, especially in towns and rural areas, where other services are not near or taking a home sample/test alone is not desirable. Would help make pharmacies a place to access PrEP.</p>	<p>Free HIV tests should be accessible through pharmacies and POCT should be offered where practicable.</p>
<p>Termination clinics</p>	<p>NICE guidelines 2016 recommend testing on first attendance and repeat testing.</p> <p>BASHH, BHIVA and BIA guidance 2020- all patients accessing should be offered a test and recommends an opt-out approach.</p>	<p>Unclear responsibility.</p>	<p>Not routinely implemented.</p> <p>This will also be necessary for this setting to become a place to access PrEP.</p>	<p>Opt-out HIV testing should be routine.</p>
<p>Addiction and substance misuse services</p>	<p>NICE guidance 2016 – routine HIV testing in ‘drug dependency services’.</p> <p>BASHH, BHIVA and BIA guidance 2020- all should be offered a test and recommends an opt-out approach.</p>	<p>Local authorities through the public health grant.</p>	<p>Unclear but commissioning framework doesn’t support routine testing in these settings. Some done as part of broader BBV testing initiatives. PHE reports high level of missed opportunities to diagnose people living with HIV who inject drugs.</p>	<p>HIV testing (as part of BBV testing) should be routinely provided on an opt-out basis for those accessing addiction and substance misuse services.</p>

Testing outside traditional healthcare settings

Most of the above has been focused on increasing and normalising testing opportunities in healthcare settings. This is, however, only one piece of the puzzle. Online and community testing play a vital role. In 2019, PHE reported that 25,514 self-sampling test kits were returned via the national HIV self-sampling scheme alone [7]. Community HIV testing describes testing which is generally led by voluntary and community sector organisations and that is delivered by and for communities it targets. PHE has in recent years tried to capture data on community testing to demonstrate the contribution and impact. 35,095 tests were reported through PHE's 'Survey of HIV Testing in Community Settings' in 2019 [xiv] [8].

Test reactivity in self sampling and community tests was 0.5% in both services. This compares with 0.2% in specialist sexual health services, 0.6% in A&E departments, 0.3% in GPs in extremely high prevalence areas and 0.7% in prisons. Community testing services are a proven tool in reaching people who are not accessing traditional health services.¹⁹ Well designed, community-led and culturally competent testing can overcome some of the barriers to testing we see such as concerns around stigma, lack of trust in services, or low perception of personal risk. It also provides opportunities to open up conversations about HIV and sexual health, providing a gateway to broader services.

At a local level, funding of community testing is highly inconsistent. Targeted peer-led design and delivery is critical but it can be difficult to achieve economies of scale and this does not fit easily with the direction of travel towards larger scale integrated sexual health service contracts. Community testing is often de-prioritised or traded-off against online testing – but these are not an either/or but rather are services often meeting different needs that are both critical components to a whole-systems approach to testing.

National AIDS Trust's Community Testing Toolkits, developed with experienced providers across England, are an invaluable resource for community organisations and funders to design and evaluate good HIV testing interventions. Local commissioners need to be supported through a national HIV testing programme to appropriately invest in them to the necessary extent to drive innovation in this area.

Optimising online and community testing

Availability of online testing is dependent on local authority buy-in to the variety of services available (including the National Home Sampling Service and the London Sexual Health Programme). Terrence Higgins Trust runs HIV Prevention England (the national HIV prevention programme) and coordinates National HIV Testing Week – the only time that online testing is available for free across the country apart from for a limited time during the COVID-19 pandemic. It has significantly increased traffic to online self-sampling services. COVID-19 showed how critical online options are when there are limitations on face-to-face services (which are experienced by some people all the time). It should not take a pandemic to make online HIV Testing an accessible option, available to all.

HIV Prevention England has similarly supported greater engagement with community testing at a local level. Local commissioners and community organisations have been able to leverage the national resources and momentum generated through HPE and testing week to increase

¹⁹Croxford S et al., 2019, Community-based HIV testing in Europe: a systematic review (Poster), HepHIV 2019 Conference, 28-30 January 2019, Bucharest, Romania [https://www.eurotest.org/Portals/0/PS4_04.pdf]

engagement with their services. This is an example of how a national programme can support local amplification of HIV testing interventions. It was shown to be successful at reaching key populations, gay and bisexual men, Black African communities and first time testers. This impact could be increased with greater investment to extend reach.

“I live in an area where STI testing is otherwise only available from a clinic that’s open for 3 hours once a month. I’m physically disabled and can’t get there easily. Being able to get tested at home is so much less taxing on my health, and I appreciate it being an option.”

SH:24

In addition, Terrence Higgins Trust has been running an online self-testing service for HIV since 2016, supplying more than 43,000 tests since launch. It has demonstrated clear demand and acceptability for self-testing among its target audience. 12% of orders have been from Black African people. Unlike self-sampling, users read their own result at home and are prompted to report their test results, with more than 60% doing so.

Since 2018, Terrence Higgins Trust’s self-testing service has also offered a free Click and Collect option, with 4,000 collection points across the UK. This has been used by nearly 10% of those ordering, including 13% of Black African people and 13% of BAME men who have sex with men (MSM). It is clear, both self-testing and Click and Collect options for broader postal testing have a role to play in improving access.

HIV testing beyond key populations

Increasing the visibility of HIV testing to a wider audience is also critical and should be a core component of national investment. According to PHE, “While Black Africans remain one of the main groups likely to be diagnosed with HIV amongst heterosexuals, they only constitute about 40% of heterosexuals diagnosed with HIV in 2018. There isn’t a clear strategy or plans to effectively target the other communities from which the 60% of new diagnoses amongst heterosexuals came from in 2018.” Again, the necessary effort and investment to meet this challenge cannot be achieved by simply carrying on as we are. Local areas are not equipped with the necessary resources or tools to reach the testing capacity that this challenge demands.

Opportunities to identify undiagnosed HIV are hugely limited by the current system and its approach to testing. We must find those who are not yet diagnosed to reach our goal and this will take a radical upscale in HIV testing. HIV testing must become standard in healthcare, with increased opportunities for screening programmes, such as in emergency departments. Not being offered or turning down an HIV test should be an exceptional event. This requires a significant shift in emphasis to opt-out rather than opt-in testing. Structural problems within the NHS that prevent this from being funded must be resolved through national support. This will reduce the number of late HIV diagnoses and prevent onward transmission, while also supporting re-engagement into care for those who need it. COVID-19 and the ‘test and trace’ moment has demonstrated the importance of numbers when it comes to testing and this is now something that resonates with the public. Now, more than ever, it is vital that upscaling testing efforts is at the core of our HIV response.

“A number of people did not want to self-test and would strongly prefer to go to a service where they could also have a conversation about their sexual health.”

LGBT Foundation

We are recommending that testing become routine and an opt-out approach is adopted because a single approach to upscaling testing efforts will not address the inequalities in our testing systems.



Health Equity Considerations

- The implementation of testing guidelines remains patchy which results in regional inequalities.
- Late HIV diagnosis remains unacceptably high with 48% of those diagnosed for first time in 2019. Levels are higher amongst heterosexuals as compared with gay and bisexual men with Black African men affected acutely. Encouraging regular testing among heterosexuals remains a challenge.



Stigma Considerations

- In specialist sexual health services in 2019, 35% of people eligible for an HIV test were not tested. Half of those eligible were not offered a test, with the other half declining a test. We know that stigma significantly limits the uptake of HIV testing services. This is well documented particularly for Black African communities.²⁰



ACTION 4

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

²⁰National Institute for Health and Care Excellence (NICE). *HIV testing: encouraging uptake*. <https://www.nice.org.uk/guidance/ng60/evidence/barriers-to-hiv-testing-final-full-report-ph33-pdf-2727985357>



COVID-19 has accelerated an already emerging trend towards digitisation of services. At the time of writing, some services have resumed face-to-face appointments as COVID-19 measures change, but further lockdown risks reversing this progress. The All-Party Parliamentary Group on HIV and AIDS report on COVID-19 and HIV²¹ found that ‘emerging anecdotal²² and survey evidence²³ indicates that some sexual activity did continue throughout the crisis and that it resumed faster than services returned’.

The potential for more technology to become part of a care pathway has only increased as a result of the changes brought about by COVID-19. As this happens, we again must be sensitive to the fact that this provides different barriers to access, particularly related to digital poverty. UK-CAB’s survey about the experience of COVID-19 in June 2020 found that 9% of people surveyed would not feel comfortable talking to their doctor over the telephone, with many indicating that this was because they had not shared their HIV status with people they lived with.²⁴ As digital ‘telehealth’ approaches become increasingly commonplace, we must consider this, and not adopt a one-size-fits all approach to care but give people more options.

We also learned there is a need to increase community testing as part of our HIV testing options. It can be particularly effective at addressing stigma and encouraging people to test. Stakeholders in Brighton and Hove were incredibly proud of the Martin Fisher Foundation’s award-winning HIV test vending machine in the city’s saunas.²⁵ The machine, supported by the Public Health England’s HIV Innovation Fund grant, enables the quick collection of demographic information, as well as giving users the option to input further information on sexual history, experience of testing and HIV result.²⁶ A further four vending machines have now been rolled out in the city, with 885 tests carried out. This is one example of a particularly innovative way of community testing, but we heard of many others. The key is that testing in communities can be targeted and flexible, and so as the HIV epidemic continues to change across the next 10 years, it must be an essential part of a universal testing strategy.

Online testing and telehealth offer us an opportunity to greatly reduce spatial inequalities, particularly between cities and rural areas. We heard from many patients and support services emphasising that care accessibility is unequally distributed across the country.

*“I have to travel a 50-mile round trip to my nearest HIV specialist ...
I am employed and struggle making the journey.”*

Carl

This is a clear barrier to accessing care, particularly when people living with HIV need to have clinic appointments at least twice a year. Kernow Positive Support and Integrated Sexual Health Services for Herefordshire Solutions 4 Health both emphasised the different barriers faced by rural communities in accessing HIV prevention and care.²⁷ In Herefordshire, low HIV prevalence leads

²¹All-Party Parliamentary Group on HIV and AIDS. COVID-19 and HIV, October 2020 <https://www.appghivaid.org.uk/projects>

²²Nam website. *A quarter of gay men report casual sex during UK lockdown*, Roger Pebody, 11 June 2020.

²³GMI Partnership: *Sex During COVID-19 Survey*, 2020 <https://www.gmipartnership.org.uk/sex-during-covid-19-survey>

²⁴Sparrowhawk, A. 2020. COVID-19: Impact on the community. BHIVA Virtual Conference 2020, 3 July 2020

²⁵The Lawson Unit Brighton, *Submission to the HIV Commission*, January 2020.

²⁶The Martin Fisher Foundation, *Submission to the HIV Commission*, January 2020.

²⁷Integrated Sexual Health Service for Herefordshire Solution 4 Health and Kernow Positive Support, *Submissions to the HIV*, January

to late diagnosis, amplified by stigma around testing and HIV. Similarly, Kernow Positive Support which supports communities in Cornwall, highlighted how hard it is to raise awareness and reduce stigma in rural communities. This is not just a problem in the countryside, but nonetheless one that we heard prevents access to care. There is significant variation in services across cities too: with an attendee in Bristol reminding us that while the city has good support services, 10 miles away in Bath it was a hugely different picture.²⁸

Adopting new technologies

Alongside adopting innovation in testing, we must be able to adopt improved prevention and treatments as they emerge. We heard how those living with HIV and members of higher risk communities are still deeply cautious of getting excited about new treatments and prevention methods which could be game-changers, because of the experience of delayed PrEP commissioning. Initially, NHS England argued that it would not fund PrEP, arguing that prevention was not part of its commissioning responsibility. After a landmark legal challenge by National AIDS Trust in 2016 and a wide-ranging campaign involving many organisations and activists across the HIV sector, the Court ruled that NHS England could legally commission PrEP in England. NHS England accepted responsibility for commissioning the drug, with local authorities responsible for prescribing and managing a programme, via their commissioned sexual health clinics. Following this decision, NHS England began a large-scale three-year implementation trial of PrEP (the IMPACT trial) in 2017, eventually making PrEP available to up to 26,000 people. Places were allocated around the country but demand for PrEP and available places on the trial did not always correlate, resulting in at least 15 people on waiting lists becoming HIV positive.²⁹ There are lessons from the PrEP roll out in other countries that also needs to be considered when making policy going forward.

The experience of having to use the law to force the NHS to consider commissioning PrEP remains a fresh example for many that just because something is cost-effective and proven to reduce the risk of HIV, does not mean it will be accessible.

“The sector must learn lessons from the delayed routine commissioning of PrEP and improve the relationship between NHS England and local authorities to ensure non-delayed access to future HIV preventatives.”

UK-CAB

When people have access to a range of options, take up increases as different methods meet different people’s needs, as is also true with contraception.³⁰ New biomedical prevention technologies, including vaccines, different formulations and methods of delivery of PrEP and antiretroviral medications (such as via long-acting injection or implant) are in development and likely to be licensed before 2030 and are important further tools in our shared aim to end

²⁸HIV Commission Evidence Hearing, Bristol, January 2020.

²⁹BBC news, HIV Diagnosis for 15 men waiting for drugs on NHS. www.bbc.co.uk/news/health-49925389.

³⁰Lessons learnt from the history of contraception are relevant for the implementation of PrEP. [Online] January 2016. <https://www.aidsmap.com/news/jan-2016/lessons-learnt-history-contraception-are-relevant-implementation-prep>.

new transmissions. Delays in commissioning PrEP show that in order to deliver new medical technologies quickly and widely, planning must begin before they are ready for us. New delivery methods may make adherence easier for both HIV treatment and prevention and may also be more discreet, making it more acceptable to people.³¹ While there is no certainty on timings for new innovations in the pipeline, options that could be available in the next 10 years include:

- New antiretrovirals
- Implants of PrEP and antiretrovirals
- Injectable PrEP and antiretrovirals

While England has been in the forefront of HIV treatment and prevention, the lack of a national PrEP programme has impacted the nation's reputation as a world leader. Lessons from this experience should inform any future commissioning of biomedical interventions, including considerations of structural capacity and budgets. The roll out of any new prevention and treatment options requires concurrent awareness raising.



Health Equity Considerations

- Experience of PrEP uptake in the UK shows that awareness and use is highest among gay and bisexual men who are white, well-educated employed, and young (25-40). If new technologies are available, tailored efforts will be required to ensure this inequity is not replicated.



Stigma Considerations

- Discrete formulations of PrEP and treatment may reduce visibility of HIV infection or prevention activity and so negate stigma, but not challenge stigma.



ACTION 5

The health and HIV care system must be able to adopt innovations more quickly and consider equitable access to innovation at every stage of planning and implementation. This includes in telehealth, online testing, and new biomedical technologies.

³¹Lessons learnt from the history of contraception are relevant for the implementation of PrEP. [Online] January 2016. <https://www.aidsmap.com/news/jan-2016/lessons-learnt-history-contraception-are-relevant-implementation-prep>.

Partner notification

As progress is made in locating those with an undiagnosed HIV infection, the people remaining undiagnosed will prove harder to find. Strengthening the delivery of effective partner notification – where trained health workers ask people diagnosed with HIV about their sexual partners or drug injecting partners, and with their consent offer them an HIV test – will be an essential response to this. Partner notification is an incredibly effective tool for diagnosing HIV, but is often not prioritised by commissioners of sexual health services.

In England in 2019, 1,705 people attended sexual health services for an HIV test as a result of partner notification, with an overall positivity of 4.6%. This is 30 times the HIV test positivity rate in specialist sexual health services overall (0.2%). This much higher testing positivity rate means it is likely that partner notification is cost effective compared with general testing policies. As new cases of HIV become increasingly less common, partner notification will become even more valuable in our efforts to trace people who may have had contact with HIV. This is a complex activity, which requires skill and resources.

Contact tracing is not new to sexual health, but in recent months it has also become a central part of the government's strategy for controlling the spread of COVID-19. We hope that changes in public awareness of this strategy created by the 'test and trace' moment will support partner notification efforts, as virus control becomes a bigger part of all our daily lives. We must capitalise on this opportunity to normalise HIV testing and partner notification as part of virus control, as this strategy will become even more important as the numbers of undiagnosed HIV infections fall.



Health Equity Considerations

- Community engagement and involvement in developing and tailoring appropriate partner notification options could address inequalities in late diagnoses.



Stigma Considerations

- Partner notification activities must consider that HIV stigma can interact with stigma related to sexual behaviours, gender identity and sexuality.



ACTION 6

Partner notification should be prioritised by local government, particularly in relation to key populations.

EQUITY

Address social and structural barriers to HIV testing and treatment access.

In 2019, Public Health England stated that gay and bisexual men, Black Africans and people born abroad are the three key population groups disproportionately at risk of HIV.³² This information helps to determine targeted interventions to reduce the burden felt by particular groups. Within these groups, sub populations are more at risk. While all groups experienced a decline in diagnoses between 2018 and 2019, there was a 14% increase in Black African gay and bisexual men, and a 44% increase in Black Caribbean gay and bisexual men between 2017 and 2018. For heterosexuals, the pattern reverses: there has been less progress for white heterosexuals compared with Black African and Caribbean heterosexuals.

We heard from many stakeholders who emphasised the need to think about intersectionality in our work. We know that often gender, race, sexuality and country of origin interact and that considering sub populations and emerging groups is essential if we are to prevent new transmissions. We also know that there has been little recent progress in reducing diagnoses in women from Black African, Black Caribbean, Black other and mixed/other ethnicity group, for example. People of Latin American and West African ethnic origin represent two of those key populations where progress seen for other groups has not been replicated. We heard from minority led groups who told us that too often, the differences within populations is not reflected in services and interventions.

In our targets for ending new transmissions, we are clear that progress must be equal across population groups and regions. By 2025, we must have reduced new HIV transmissions by 80%, which would mean 900 new transmissions across England. Our target data table breaks down these target population groups, so that progress can be measured not just on a fall in new diagnoses overall, but within groups. Without this, we will ultimately not be able to end new HIV transmissions in England.

Women

Women make up a third of people living with HIV, with an estimated 31,000 women living with HIV in the UK. As a group, women do not experience the best HIV outcomes: 52% of women diagnosed in England in 2019 for the first time were diagnosed with HIV late (above the average of 48%) and women are not experiencing the same rates of decrease in new diagnoses as other populations. With this in mind, it is not a surprise that women often feel invisible in the response to HIV in the UK, reporting they feel ignored or not taken seriously by healthcare staff and researchers.³³ 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.³⁴ This contributes to the fact that women are more likely to get their diagnosis

³²Public Health England, HIV in the United Kingdom: Towards Zero HIV transmissions by 2030, 2019.

³³Sophia Forum, Terrence Higgins Trust. Women and HIV Invisible No Longer A national study of women's experiences of HIV. [Online] 2019. https://www.tht.org.uk/sites/default/files/2018-08/women-and-HIV_report_final_amended.pdf; *A Systematic Review of the Inclusion (or Exclusion) of Women in HIV Research: From Clinical Studies of Antiretrovirals and Vaccines to Cure Strategies*. Curno MJ, Rossi S, Hodges-Mameletzis I, Johnston R, Price MA, Heidari S. 71, 2016, *Journal of Acquired Immune Deficiency Syndromes*, Vol. 1, pp. 181-8; *Where Were the Women? Gender Parity in Clinical Trials*. Goldstein RH, Walensky RP. 26, 2019, *The New England Journal of Medicine*, Vol. 381, pp. 2491-2493.

³⁴Public Health England. Trends in HIV testing, new diagnoses and people receiving HIV-related care in the United Kingdom: data to the end of December 2019 (November 2020)

at the GPs, antenatal clinics or at other hospital outpatient departments. We both need to be reaching more women with tests in sexual health clinics and in other preferred settings.

The demographic of women with HIV has broadened in recent years. Fewer HIV diagnoses are made in Black African women (although they still make up 34% of new HIV diagnoses), and new diagnoses are increasingly likely to be UK-born, white or another minority ethnicity and aged 50 or older. Currently in the UK, 4 out of every 5 women living with diagnosed HIV are migrants and 3 in 4 are from minority ethnic communities. There is little knowledge or research to understand who women at risk of HIV are. This holds back interventions targeted at a key population in the HIV response.

The way women's sexual and reproductive health interacts is often neglected in the HIV response. For example, women living with HIV continue to experience high levels of menopausal symptoms, which often go under-managed and therefore impact their quality of life and engagement in care.³⁵ Instances where women access sexual health services represent an opportunity for an increase in HIV testing of women, while also addressing misconceptions about who is affected by HIV.



Health Equity Considerations

- Most women were not able to access the PrEP IMPACT Trial. This means that they are delayed with PrEP access and information on access and will remain so even when PrEP is routinely commissioned.
- Despite evidence that antiretroviral therapies work differently in women and men, women are underrepresented in all types of HIV clinical research.



Stigma Considerations

- HIV stigma often intersects with discrimination based on gender, as well as ethnicity, migration status and/or age that also affect the lives of women living with HIV.
- The 'invisibility' of women in the HIV response perpetuates stigma that women are not affected by HIV.

³⁵The association between menopausal symptoms and adherence to antiretroviral therapy in women living with HIV. Solomon DF, Burns F, Rolland A, Sabin C, Sherr L, Gilson R, Tariq S. Amsterdam : AIDS 2018, 2018.

Gay and bisexual men

Since the beginning of the HIV epidemic, gay and bisexual men in England have been disproportionately impacted by HIV. The community makes up an estimated 2.6% of the UK population but 47.8% of all people living with HIV, making gay and bisexual men the group most at risk of HIV acquisition in the UK. This association has impacted generations of gay and bisexual men's relationship to sex and identity. Further, the historical and current interaction of HIV stigma and homophobia has led to entrenched misconceptions that only gay and bisexual men are at risk of HIV.

Although overall gay and bisexual men have seen the most progress in falling new diagnoses rates, this has not been distributed evenly across subpopulations within the community. Black (both African and African Caribbean) gay and bisexual men remain disproportionately affected by HIV. For Latin American and South East Asian gay and bisexual men, there has been an increase in HIV prevalence over recent years. Young men have also not experienced a decrease in new HIV diagnosis. Trans and bisexual men have often been left out of these prevention messages. Therefore, we must remember both that the burden of HIV remains high for all gay and bisexual men and that this is not a homogeneous group. Targeted interventions have meant a significant overall reduction in transmission, but still some are not part of these successes.

Gay and bisexual men are not only disproportionately affected by HIV but overall, by poor sexual health and STIs. In particular, there has been a rise in syphilis and gonorrhoea in this group. There has also in the past 15 years been a significant increase in chemsex across all groups of gay and bisexual men, and a recent study suggested HIV positive men living in the UK reported higher levels of chemsex compared with three other European countries.³⁶ Running parallel to this trend, other changes in gay culture such as the closure of LGBT spaces has led to reduced opportunities to interact with gay and bisexual men and disseminate information in traditional ways. We don't fully understand the impact of apps like Grindr and social media on these patterns, but they have created different ways for men to engage and meet for sex which has undoubtedly changed things. This presents both challenges and opportunities for health promoters to engage and disseminate prevention messages.

In addition to sexual health, there are distinct but overlapping areas in which gay and bisexual men bear a disproportionate burden of ill health: particularly in mental health, in the use of alcohol, drugs and tobacco and experiencing discrimination in healthcare.

Debates around whether to name this population group based on behaviour or identity 'men who have sex with men' (MSM) or 'gay and bisexual men' (GBM) are ongoing. Some men who have sex with men do not identify as gay or bisexual and do not engage with LGBT+ services. They, therefore, may be less informed about prevention and support but still at risk of HIV. However, many gay and bisexual men feel that the acronym 'MSM' medicalises their identity or perpetuates self-stigma and shame. In 2018, Public Health England's annual report on HIV in the UK used the term Gay and Bisexual Men to identify this group for the first time.

³⁶NAM aidsmap. *HIV-positive gay men in England report highest chemsex rates in four-country survey*. [Online] November 2019. <https://www.aidsmap.com/news/nov-2019/hiv-positive-gay-men-england-report-highest-chemsex-rates-four-country-survey>.



Health Equity Considerations

- HIV affects gay and bisexual men disproportionately. Gay and bisexual men make up 46.1% of the community living with diagnosed HIV in England.
- Gay and bisexual men are more likely to be living with HIV if they are Black or minority ethnic, migrants and/or younger.
- There has been a steady increase in HIV prevalence amongst men from Latin American and South East Asian communities.
- Mental health issues are up to seven times more common in gay and bisexual men as compared with the general population.
- Gay and bisexual men are also less likely to access primary care.



Stigma Considerations

- As the epidemic has had such a direct association with gay and bisexual men over forty years, HIV stigma is entangled into the community and interacts with homophobia.
- HIV stigma and homophobia can compound to lead to discrimination in healthcare settings.

Black, Asian and Minority Ethnic communities

The term BAME is used as an umbrella term to encompass diverse, complex communities. It often obscures the specific health needs of groups which are not homogeneous. BAME communities are overall more likely to be living with HIV, and particularly Black African communities are disproportionately affected by HIV. Black Africans are identified by Public Health England as a key population living with 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 (59%), Black Caribbean (48%), Black other (47%), Asian (46%), Other / mixed (40%) the next ethnic groups most 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. Some ethnic groups are not effectively captured by the data collected by GPs and sexual health clinics, which has implications for reports, funding and research opportunities.

For example, groups categorised as 'mixed/other' include many ethnic groups with different needs, for example Latin Americans and various groups from the Middle East. This 'mixed/other' group makes up 11% of those diagnosed with HIV in 2019 in England, the next largest group after white people (57.4%) and Black African (19.2%). While the 'mixed/other' group is the least likely

to be diagnosed late (40%) this may hide trends in subpopulations that are not identifiable in the current surveillance data. Although country of birth is recorded, this is not sufficient for identifying the risk factors of second and third generation migrants.

Alongside the severe health inequalities experienced by Black, Asian and Minority Ethnic communities, there are multiple barriers to accessing appropriate services. This can include language, cultural barriers, stigma, homophobia and heteronormativity. As a consequence, BAME people living with HIV often feel less informed about their condition. This is exacerbated by the context of hostile environment policies and the Windrush scandal, which make many BAME people reluctant to access services. Despite knowledge of the disproportionate effect of HIV on BAME communities old mistakes were repeated in recruitment for the PrEP trial and uptake among BAME communities has been very low. When routine commissioning is introduced, this means concerted effort must be made to remedy this inequality. We know what works: community-led responses are most effective in creating changes, and there is a need to recognise the expertise and leadership of BAME individuals and organisations in any strategies and plans to prevent new HIV transmissions within BAME communities.



Health Equity Considerations

- Black and minority ethnic people are consistently more likely to experience inequalities in health, including in mental health.^{37 38}



Stigma Considerations

- To improve up-take of services, support which is better culturally, linguistically and faith tailored is needed.
- Tailored interventions must avoid stigmatising communities.

Young people

The cohort of young people (under 25s) living with HIV in the UK is among the most marginalised of groups of people living with HIV. This group includes children who acquired HIV through vertical transmission (at birth and through breast feeding) and adolescents who acquired HIV through sex.

One of the biggest success stories of HIV in England is the tiny rate of vertical transmission from diagnosed women in the UK (less than 0.3% of those who become pregnant). This is in part the result of routine antenatal screening, which identifies undiagnosed HIV in pregnant women. This means that pregnant mothers living with HIV can quickly initiate antiretroviral therapy, which prevents transmission. Testing for HIV in antenatal services is opt-out, which makes HIV testing feel like a regular part of a pregnancy health check.

We have much to learn from the success of this policy. Since 2012, there have been decreases in recorded new diagnoses of HIV amongst under 15s, with 15 new diagnoses in this age group

³⁷Evandrou, Maria, et al. Ethnic inequalities in limiting health and self-reported health in later life revisited. *Epidemiology and Community Health*. 2016, Vol. 70, 7.

³⁸Examining ethnic inequalities in health and tenure in England: A repeated cross-sectional analysis. Darlington-Pollock, Frances and Norman, Paul. 82-90, s.l. : Health and Place, 2017, Vol. 46.

in 2019. In the age category of 15-24, there has been a fall in new diagnoses since 2015, but still 294 children and young adults between 15 to 24 years were diagnosed in England in 2019. In the UK, 20% of young people living with HIV are currently not virally suppressed.³⁹

The transition from paediatrics to adult clinics at 18 is not always a smooth one for young people living with HIV and some drop out of care altogether. In the UK there is a large gap in services, and young people report feeling that services do not feel tailored to their needs.⁴⁰ Children leave behind a multidisciplinary team who have worked them for an average of 11 years and lose much of the holistic support they received as an under 18, including psychosocial support. This stage of adolescence is recognised as a critical period for developing self-management skills and building the foundations for good health in adulthood. Outcomes for long-term conditions are not as good in adolescents as in children and adults, which could be linked to the poorly planned transition from paediatric to adult care.⁴¹ Often stigma leads young people to go to their HIV Consultant for other health needs so as to not have to share their HIV status with other healthcare professions. When new to adult HIV services, this can lead to further health inequalities as minor health problems are not resolved.

Another critical factor for this cohort is education: both for prevention and challenging stigma. Children and young people living with HIV and at risk of HIV need to be informed about what HIV is and the treatment and prevention available. Young people living with HIV need the skills to negotiate health, relationships and sex as part of their development. They also need their peers to have this knowledge and awareness, so they do not have the burden of educating others to prevent stigma. For young people at risk of HIV, particularly young gay and bisexual men, who often are not informed of HIV prevention methods at school, this is compounded by experiences of potential marginalisation and prejudice from peers, family or community.

³⁹CHIPS – Collaborative HIV Pediatric Study. [Online] <http://www.chipscohort.ac.uk>.

⁴⁰CHIVA Guidance on Transition for adolescents living with HIV, CHIVA, 2017: https://www.chiva.org.uk/files/2814/8587/2242/CHIVA_Transition_Guidelines2017.pdf

⁴¹Growing up with perinatal HIV: changes in clinical outcomes before and after transfer to adult care in the UK. al, Judd A et. 3, London : Journal of the International AIDS Society, 2017, Vol. 20. 21577.



Health Equity Considerations

- We know that young people growing up with HIV often face unequal life chances and live in disadvantaged circumstances without access to relevant information and support.
- Organisations that work with young people told us that even within the activist community, young people often don't feel heard.
- Half of children growing up with HIV in the UK were born abroad, and many have been or remain in the asylum system and face related social and economic challenges.
- Young gay and bisexual men are less likely to be informed about HIV prevention and therefore are more likely to be at risk of HIV.
- Young people are less likely to start treatment within 3 months of diagnosis.⁴²



Stigma Considerations

- Many young people report feeling anxious and sometimes avoid romantic relationships.
- Organisations that work with young people told us that they are often told to not talk about HIV by families when growing up, which can lead to trauma and self-stigma. HIV is often not named to children until a late stage, although the Children's HIV Association recommends that HIV is named to children from the age of six.⁴³
- Lack of education and support, accompanied by stigma around sexuality, all contribute to vulnerability to HIV infection.
- Currently, the U=U message is not targeted at young people, for fear that this could lead to irresponsible sex. This does nothing to challenge stigma in this group and disempowers young people at a critical stage in their life.

People who inject drugs

HIV prevalence amongst people who inject drugs (PWID) in the UK remains low (1.2%), but estimates suggest that the risk of contracting HIV for this group is 22 times greater than for people who do not inject drugs. This group is susceptible to focused outbreaks, and this is currently ongoing in Glasgow and South West England. We also know that prevalence could be higher than the data we have, because, for example, a new HIV diagnosis in a gay man involved in chemsex tends to be recorded as a 'men who have sex with men' diagnosis. While the needs of those involved in chemsex may be different to other drug users, both need to be addressed in all their nuance if we are to end new HIV transmissions.⁴⁴

⁴²Public Health England. *HIV in the United Kingdom: Towards Zero HIV transmissions by 2030. 2019 Report*. London: Public Health England, 2020.

⁴³<https://www.chiva.org.uk/guidelines/naming-hiv-younger-age-chiva-statement/#>

⁴⁴NAM. Gay and bisexual men with problematic chemsex are a diverse group with significant sexual and psychosocial risks. [Online] 2019. <https://www.aidsmap.com/news/jul-2019/gay-and-bisexual-men-problematic-chemsex-are-diverse-group-significant-sexual-and>.

Chemsex is particularly relevant in the country's HIV response. While the number of people injecting drugs before or during planned sexual activity is very low, they are at a very high risk of transmission of HIV, hepatitis B and C and other STIs. While historically chemsex has been associated with gay and bisexual men use, there is an emerging anecdotal evidence suggesting that increasingly chemsex goes beyond gay and bisexual men.

We have seen that successful stories come from places with greater collaboration between sexual health and drug and alcohol services (including chemsex). They look into addressing the complex needs of individuals (for example, homelessness, poor mental health and poverty) and making engaging with support services easier to them. However, significant cuts to drug treatment services (by 26% since 2014/15) alongside cuts to sexual health budgets have affected the ability to form these partnerships. The Advisory Council on the Misuse of Drugs reported that reductions in local funding are the single biggest threat to drug misuse treatment recovery outcomes being achieved in local areas.



Health Equity Considerations

- People who inject drugs are among the most marginalised groups and often face severe barriers to accessing services. PWID are more likely to be diagnosed late (46%).



Stigma Considerations

- The criminalisation of drug use has led to stigma where PWID are reluctant to access services from testing, counselling and to wider social care.
- Among older populations of PWID, there is greater stigma and fear around HIV (in part from "death sentence" media campaigns of 1980s) which contributes to their low engagement in prevention work.

Trans communities

Literature on trans people and HIV is full of gaps and "more research is needed"; but among available studies, we know there is a high HIV prevalence in the trans community with a heavy burden of HIV on trans women.⁴⁵ Trans people in England face social exclusion, economic vulnerability, and are at an increased risk of experiencing violence. Systematic disempowerment of the community has had a direct impact on their sexual health, in particular around negotiating safer sex practices.

There was a long history of no national data on trans people living with HIV since the beginning of the epidemic. This started to finally change in 2015 when new HIV diagnoses cases among trans people started to be recorded. The impact of HIV among trans people in England before

⁴⁵The term trans is used as an umbrella term that refers to all people whose gender identity is different to the gender given at birth, this includes trans men, trans women, non-binary, and other gender identities. When appropriate, this report will disaggregate the term to refer to a specific community within trans.

2015 remains widely unknown. In 2017, a new code to record trans people attendance to sexual health services was introduced. The commission learnt that the use of this code is yet to be fully implemented. All this makes it harder to fully understand the impact of HIV among trans people and how to best address their needs.

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.⁴⁶

Trans led organisations have been effective at engaging with trans people. They have been successful at using holistic and asset-based approaches to the health and wellbeing of the community. As such, community-led efforts should be at the centre of decision making and programme delivery of HIV interventions addressing the needs of the trans community. Without organisations like cliniQ trans take up of the PrEP IMPACT Trial would have been very different – this should be considered with the roll out of routine commissioning of PrEP.



Health Equity Considerations

- Trans communities experience an inequality and lack of access to informed health services in the UK. Clinical lack of knowledge and cultural awareness in every aspect of health, sexual health, HIV and wellbeing.
- Access to funding for trans health organisations is a barrier to greater prevention.
- Information on trans people in clinical trials for HIV prevention remains minimum (for example, PrEP Impact Trial, relegated to 'Women and other people').
- In addition, various studies have identified increased vulnerabilities for acquiring HIV among particular sub-groups of trans people, including young and ethnic minority trans women; BAME people; young people; migrants; and sex workers.



Stigma Considerations

- Transphobia and stigma prevent trans people accessing health services.
- Stigma impacts not only on HIV services but also primary care, mental health and data collection putting trans people at risk and increases vulnerability to ill health, both physical and psychological.

⁴⁶Government Equalities Office, National LGBT Survey Research Report, July 2018.

“If we are to reach the 2030 target, no group or geographical area can be left behind. It will be vital that epidemiological data is analysed to a granular level to unpick where inequity in progress to reduce HIV rates (and deaths) is occurring.”

Terrence Higgins Trust

Meeting the equality challenge with the right data

Greater nuance must become more than a part of our approaches going forward. In Bristol, we were told that the acronym ‘BAME’ risks becoming meaningless as a catch all term for a diverse group of people. We agree that we need to be more specific in our understanding and the language we use when addressing inequalities experienced by different communities of colour in England.⁴⁷ We heard there has been little progress in ethnic groups categorised as ‘mixed/other’ and this category is not fit for purpose. We urgently need a clearer understanding of those most affected by HIV in this group to prevent inequalities being perpetuated. We recommend that data collection systems are updated to reflect this, including options to record Latin Americans and people from the Middle East. Without this clearer information, we are unable to target interventions towards these groups. Unhelpful generalisations are also used in data collected about women living with HIV in England. Current data collections record all women as heterosexual, meaning that there could be a significant amount of data missing on bisexual and lesbian women.⁴⁸ At the very least, data and research should use known route of transmissions rather than assuming all women living with HIV are heterosexual.⁴⁹

Most importantly, over the next 10 years that system must be able to respond to even small changes in the data in order to effectively tackle HIV. We cannot stop at having better data. We must use this better data to inform our approach to ending new transmissions. Communities are not ‘hard to reach’, we just need to adapt our tools to better reach them.⁵⁰

“The inclusion of the ‘Latin American’ community in the surveillance system is crucial if we want to tackle the poor health outcomes among this community. Local Authorities need to collect and report data on the special health needs of the Latin Americans.”

Coalition of Latin Americans in the UK

⁴⁷HIV Commission Evidence Hearing, Bristol, February 2020.

⁴⁸LGBT Foundation, *Submission to the HIV Commission*, January 2020.

⁴⁹Terrence Higgins Trust, *Invisible No Longer: Women and HIV*, 2018.

⁵⁰HIV Commission, Bristol Evidence Hearing, January 2020; NAZ, *Submission to the HIV Commission*, January 2020.



ACTION 7

Maximise the flexibility and granularity of data collection systems to meet the changing face of HIV and tackle inequity, including reporting on all communities with over 500 cases of new transmissions in the last 5 years.

Late diagnoses

To end new HIV transmissions by 2030, we must end the cycle of late diagnosis. Since 2015, there has been no improvement in the percentage of people diagnosed late in England. Between 2016 and 2019, the percentage of all newly diagnosed who were diagnosed late has fluctuated around the high 40%⁵¹. Certain groups are more likely to be diagnosed late, for example 59% of heterosexual men diagnosed in 2019 were late diagnoses. The number of late diagnoses is not the perfect indicator of how good the system is at finding a new case of HIV, because a rise in late diagnoses could represent a short-term improvement in finding those undiagnosed. There are currently an estimated 5,900 people living in England with an undiagnosed HIV infection and it is imperative that they are tested and diagnosed.⁵²

However, in the long term, these levels represent a failure of the system. That's why we think every person in England should know their HIV status. We were shocked how a lack of awareness of the risk of HIV, particularly among healthcare professionals, can put people unaware they are living with HIV in dangerous situations. For example, the belief that a heterosexual woman could not have HIV, despite presenting symptoms, had life-threatening consequences for an evidence hearing attendee.⁵³

“I did not think HIV was a risk for me ... nor did my GP. So HIV testing was never really thought about until I was ill and in hospital.”

Ben Cromarty

A person living with HIV is considered to have been diagnosed late if they test positive for HIV after the virus has already started to damage their immune system (when they have a CD4 count below 350). Being diagnosed late increases the risk of dying by eight-fold and it is estimated that someone who is diagnosed very late with HIV has a life expectancy at least 10 years shorter than someone who starts treatment earlier. It is also likely that people diagnosed late have been living with an undiagnosed infection (for three to five years) and so may have been at risk of passing on HIV to partners. In 2019, 48% of adults diagnosed in England were diagnosed at a late stage of HIV infection, a shocking level which requires urgent action.

⁵¹Public Health England, *HIV in the United Kingdom: Towards Zero HIV transmissions by 2030*, 2019.

⁵²Public Health England, *HIV in the United Kingdom: Towards Zero HIV transmissions by 2030*, 2019.

⁵³HIV Commission Evidence Hearing, Birmingham, March 2020.



The best way to address late diagnoses is through increased HIV testing. The sooner a person knows their HIV status, the better chance they have of improving their health and accessing HIV treatment if needed.

However, this also represents an additional challenge. As increased testing leads to more people being diagnosed during the very early stages of infection, the definition of late diagnosis (as having a CD4 count below 350) may misclassify people diagnosed who seroconverted recently – as during this period when immune systems have recently started fighting the HIV virus, CD4 counts can be lower. This could be addressed by close monitoring and investigation of each late diagnosis reported in the country. This approach would also allow us to better understand missing opportunities to identify cases earlier.



Health Equity Considerations

- Black African (59%), men who acquired heterosexually (59%), people aged over 65 year (64%), people diagnosed in the South of England (56%).
- People who inject drugs and people aged over 65 years have higher mortality rates, particularly in the year following diagnosis.



Stigma Considerations

- Misconceptions that HIV only affects some groups means that some people don't think they are at risk of HIV and so don't test.
- Healthcare staff sometimes don't think of HIV when patients present indicator conditions because of misconceptions about who is at risk of HIV.

Learning from failure

Our plan includes actions that should prevent late diagnoses; in particular, training all healthcare staff and making opt-out HIV testing routine across the health system. Alongside this, we need to change the way we approach a late diagnosis. In evidence submissions and at public hearings, we heard that the best way to do this is to treat each late diagnosis in England as a system failure and follow it with a serious incident investigation.⁵⁴ We recommend that this is the case.



ACTION 8

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

⁵⁴Terrence Higgins Trust, *Submission to the HIV Commission*, January 2020; Brighton Evidence Hearing, January 2020.

RESOURCES

Ensure there are the right resources to meet the 2025 and 2030 goals.

Funding for the HIV pathway comes from multiple sources. HIV treatment and clinical care is funded as part of the national NHS England budget, while many HIV (and other sexual health) prevention services are funded by local authority public health grants. While NHS England funded services continue to receive (much needed) increases in funding, the local authority public health grant has seen consistent cuts (14% in real terms between 2014-2018) and sexual health budgets have borne more of these cuts (being cut by 25% 2014-2018). HIV testing is currently commissioned via several pathways and testing strategies are in part determined by HIV prevalence. In order to improve diagnosis, new testing strategies will be required, and current cost-effectiveness models challenged.

We know that any response must be properly resourced to be successful. By resources, we mean financial investment but also people, knowledge and tools. This includes a well-trained and supported workforce and access to information, prevention and care for everyone. Unlike the NHS budget, public health (including sexual health) spending has not been protected and has been cut by £700 million in real terms since 2015. Cuts are already having an impact on sexual health services. In some parts of the country in services provision, lower staffing levels, and reduction of sexual health advice and prevention activities threaten the progress achieved to date. Many services are unable to meet demand, with London's largest sexual health clinic, 56 Dean Street, reporting in 2018 that they had roughly 1,500 patients a day trying to book onto 300 available appointments.⁵⁵ Support services have also felt this impact.⁵⁶

In 2016, the cost of HIV treatment per annum when HIV is diagnosed quickly was estimated to be around £14,000 per case compared with £28,000 per case when diagnosed late. Each infection per person is estimated to represent between £280,000 and £360,000 in lifetime costs to the health system.⁵⁷ These future treatment costs can be avoided by investing in HIV prevention and ending new HIV transmissions. Additional investment in HIV prevention will provide a long-term financial benefit to the healthcare system by reducing healthcare costs as a result of avoided new infections and delayed disease progression.⁵⁸

“The underfunding of community and public services at large make it even more difficult for many people on the margins to be resilient and exercise control over the direction of their own lives.”

Dr Catherine Dodds

⁵⁵<https://www.bbc.co.uk/news/uk-england-london-42771665>

⁵⁶Health and Social Care Select Committee Inquiry Report.

⁵⁷Nakagawa et al, 'Project Lifetime Costs Associated with HIV Infection', 2015.

⁵⁸Bohdan Nosyk, PHE, et al. "Ending the HIV epidemic in the USA: an economic modelling study in six cities", *The Lancet HIV* 7, no.7, 2020.

HIV care and prevention in England was already failing to meet demand before the COVID-19 pandemic hit. Now, as well as a continued shortage in resources for publicly funded interventions, many already stretched voluntary organisations are struggling to survive. The voluntary sector provides advocacy, support services, peer support, and testing. These services have often borne the brunt of cuts to funding and have been amongst the quickest to adapt in the face of the pandemic. A loss of resources has come at a time when more people than ever are living with HIV. Even if we achieve progress towards our goal of reducing and ending new transmissions, the number of people living with HIV will continue to rise. Our plan to end new HIV transmissions requires investment in prevention, so that services don't just struggle to deliver the minimum required but can innovate and accelerate our progress.

In Birmingham, stakeholders reported that the Heartlands HIV Clinic does an incredible job to support people living with HIV. Patients were proud of the clinic and had established a patients' forum for peer mentoring. However, the service is stretched and is meeting needs that should be supported by other services. In contrast to Bristol, Manchester and Brighton, there are no funded charities in sexual health in the area, which all commented on as being a big loss to the city. This is despite that fact that residents in the Midlands and East of England region contributed to the highest number of new diagnoses outside of London (23% (660 / 2,861) in 2019. Fifty percent of those living with HIV in the area were diagnosed late, above the national average. A number of responses received by the Commission noted the problems caused by the separation of HIV services commissioned by NHS England and sexual health services, commissioned now by local authorities, has been made worse by the absence of voluntary sector provision in many areas of the country.

“There also should be more acknowledgement of the prevention work that is integral within the support of HIV positive clients by the third sector, maintaining their wellbeing, giving increased assurance to treatment adherence and less risk-taking, hence, reducing HIV transmissions.”

Blue Sky Trust



Health Equity Considerations

- Reaching different key populations requires different levels of investment. Future economic modelling should be based on achieving equal outcomes rather than equal investment.
- As new communities emerge in England and are affected by HIV, we should not delay our response by waiting for economic models. Instead, as we respond we should measure and evaluate impact as a way to generate new evidence and inform economic models.
- Services in areas of low prevalence must be maintained, to protect against inequalities growing. There is variation across the country in relation to the access to peer and support services available depending on local priorities and available funding. This is likely to have a bigger impact on people who already experience health inequalities such as those from migrant, BAME and LGBT groups.



Stigma Considerations

- Any economic case for preventing new HIV transmissions must be framed by a principle that the primary goal of treatment and prevention is to improve lives and health.
- HIV care and support, including HIV-specific psychosocial care and peer support, have faced a notable decrease in funding. This work is recognised internationally as part of the HIV care continuum but not protected in the same way as treatment budgets.

If people living with HIV are given the support they need, advances in treatment mean that we will continue to see people living with HIV for many decades to come and therefore HIV clinical services that meet their needs (especially an ageing population) must be sustained. Alongside this, while the number of HIV diagnoses decrease, and it becomes more expensive to find and diagnose a case of HIV, it is likely to get more and more difficult to protect HIV specific funding, despite the fact that the needs of people living with HIV remain the same. As new technologies come to market – new ways of taking PrEP, more accessible or acceptable HIV treatments – a clear case will need to be made for why a new technology should be funded by the NHS for a health condition that is in the future, we hope, declining in prevalence.

Newly developing Integrated Care Systems allow the opportunity to develop and sustain the collaborative care models required to manage HIV as a long-term condition. NHS England is developing a Category Based Management approach to procuring and commissioning ART. This will be more closely aligned to the BHIVA Treatment guidelines and allow an evidence-based but more holistic approach to drug treatment.

Each year, local and national bodies commit significant financial resources to the fight against HIV. They help increase the reach and effectiveness of HIV services, research, health promotion and treatment. However, over £700 million in cuts to the public health budget since 2014/15 have led to sexual health service budgets being cut by 25%, impacting the provision of prevention services and risking our HIV progress to date. This is in the context of increasing demand for sexual health services and a growing population living with HIV.



ACTION 9

The Treasury and Department of Health and Social Care must understand the unmet need in the sexual health sector and provide a radical uplift in public health funding, particularly that invests in local sexual and reproductive health services.

The HIV workforce

We were deeply moved by the dedication of the HIV workforce, with many going well above their duties to care for people living with HIV and prevent new transmissions. We spoke to nurses, doctors, staff at community organisations and public health teams, who were all deeply committed to their roles and feeling stretched and burned out. Many told us that they spent additional time filling gaps and providing parts of care that they shouldn't have to have been doing. Many felt this work went underappreciated.

The sexual health, reproductive health and HIV workforce in England has never been as fully defined as other clinical specialisms. This workforce covers a broad range of clinical and non-clinical, specialist and non-specialist staff providing services from hospitals, primary care and community settings. Over the past few decades, shifts in healthcare in general as well as in the nature of HIV care have put substantial stress on the HIV workforce. There are two interrelated challenges for the workforce over the next decade: maintaining the specialised HIV workforce, while educating the general workforce better about HIV.

There are problems of retention and recruitment of the workforce across the whole HIV care pathway, which pose a problem if the UK is to maintain its status as world leader in HIV care.⁵⁹ For example, only 37% of genitourinary medicine (GUM) and HIV/AIDS physicians work full time. The commissioners of sexual health, reproductive health and HIV services rely on staff being available and suitably qualified to match to the requirements of the service. They do not, however, always commission services taking full account of ongoing training needs and how the workforce will develop in the future to meet emerging needs.

A significant decline in AIDS-related morbidity and mortality has been the big success of the world-class treatment provided for HIV in England. This means that the HIV workforce is now managing an ageing population of people living with HIV, with an increased risk of age-related comorbidities. Even as new HIV diagnoses decline, it will be decades before we see a significant decline in the total population of people living with HIV. This is welcome. We want people living with HIV in England to live long and healthy lives, and we need to maintain a workforce to

⁵⁹A workforce in jeopardy- identifying the challenges of ensuring a sustainable advanced HIV nursing workforce. [Online] Sheffield Hallam University, 2018.

facilitate that. Normal life expectancy for many with HIV, and an ongoing decline in new HIV diagnoses, will mean a population of people with HIV with an average age older than the general population. Combined with the higher rate of age-related conditions, our services must evolve to manage multi-morbidities, polypharmacy, psychosocial issues, residential/nursing care services and end-of-life care, to maintain excellent HIV care outcomes.

Success in ending new HIV transmissions by 2030 will not mean that our work is complete. Efforts to maintain our progress and ensure people living with HIV can lead healthy and fulfilled lives must continue and a trained workforce will be essential to this. Further to this, a trained HIV workforce will have a broad range of transferable skills which will make them well placed to be deployed in other public health efforts and beyond. Investment in people and skills for HIV are therefore as much a long-term investment as a shorter one to meet our 2030 goal. This has been the case with COVID-19, with many lessons already learned in HIV applicable to this new pandemic.

“Our resources to deliver such innovative and evidence-based programmes are dwindling.”

London Borough of Lambeth, Public Health Department

At the moment, within clinical settings, we risk the number of specialised clinicians falling below the number needed for prevention and care. Within the voluntary sector, we risk losing services crucial to challenging structural inequalities, like BAME and Trans-led services and those enabling excellent care outcomes for a growing number of people living with HIV.



ACTION 10

The government’s HIV Action Plan 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.

Access to HIV prevention and treatment tools

The success of combination HIV prevention is the principal explanation for the fall in HIV incidence among gay and bisexual men in England. We need to translate this progress across all populations and regions of the country. We will only achieve our goal through sustained, ongoing health promotion, which utilises all the tools of combination HIV prevention. We know from the experience of the PrEP IMPACT Trial that if prevention tools are not accompanied by health promotion activities, inequalities in access are exacerbated. Only if we commit to sustained and comprehensive promotion of combination HIV prevention will our message reach everyone.



ACTION 11

Fund and implement multi-year coordinated health promotion programmes aiming to increase access for all to the full set of combination HIV prevention options available. This should include promotion and access to PrEP, condom use, HIV testing and the role of treatment as prevention (U=U).

We have the tools available to end new HIV transmissions. Recent falls in HIV transmissions have been attributed to combination HIV prevention: an increase in HIV testing uptake, more people on HIV treatment making their viral load undetectable, continued use of condoms and the uptake of PrEP.⁶⁰

PrEP is the newest combination prevention tool. It is a drug taken by HIV-negative people before and after sex. Evidence shows that PrEP is almost 100% effective when taken as prescribed.⁶¹ Since the evidence of PrEP being effective became known, activists and clinicians worked to ensure PrEP was available via the health system as a prevention tool. Initially, NHS England argued that it would not fund PrEP, arguing that prevention was not part of its commissioning responsibility. After the National AIDS Trust's successful legal challenge in 2016 and the Court ruling on NHS England's ability to commission of PrEP, the IMPACT trial opened in 2017 with 10,000 places. Eventually this made PrEP available to 26,000 people. The cap on places had life-changing consequence for 15 people on PrEP waiting lists; each was confirmed to be HIV negative at their first assessment for the trial and are now confirmed to be HIV positive.⁶²

In March 2020, the government committed to make PrEP fully available, uncapped, on the NHS. This was a huge victory for those who have been tirelessly campaigning for PrEP to be made available through the NHS for the last five years, since the Proud Trial proved that PrEP was effective in preventing HIV transmission. Since, we have been disappointed by further delays and £5 million being cut from the £16 million budget intended to make this available. We believe it is essential that PrEP is made available, fully funded and on an ongoing basis, if we want to achieve our target.

Despite this announcement, at the time of writing, bureaucratic delays mean that in most areas of England, the PrEP service is still not available. Commissioning of PrEP will facilitate access to the sexual health pathway of care which offers an opportunity to consider sexual health and wellbeing more holistically and ensure STIs and reproductive health are also addressed. However, sexual health services should not be the only way to access PrEP on the NHS – the exclusivity risks widening health inequalities with women, BAME and trans people much less likely to access these services, let alone rural communities physically far away from this provision. The need for additional pathways to ensure equity of access including access via primary care (including non-traditional delivery for example, app-based provision of GP services), maternity, and termination of pregnancy services but also gender clinics and even pharmacies. If the high street retailer Superdrug can provide PrEP through its 'online doctor' – a welcome development – it must be possible for the NHS to provide PrEP in healthcare settings more regularly frequented by

⁶⁰Public Health England, *HIV in the United Kingdom: Towards Zero HIV transmissions by 2030*, 2019; 56 Dean Street, *Submission to the HIV Commission*, January 2020.

⁶¹Pre-exposure prophylaxis to prevent the acquisition of HIV-1 infection (PROUD): effectiveness results from the pilot phase of a pragmatic open-label randomised trial. McCormack, Sheena, et al. 10013, s.l.: The Lancet, 2016, Vol.387.

⁶²BBC news, HIV Diagnosis for 15 men waiting for drugs on NHS. www.bbc.co.uk/news/health-49925389.

all communities. As the national PrEP guidance from BASHH and BHIVA states, “limiting provision of PrEP to level 3 sexual health clinics risks widening health inequalities disproportionately among black, Asian, and minority ethnic (BAME) populations.”

Public Health England attributes recent declines in HIV diagnosis to combination prevention, the role of much wider and more frequent testing as well as rapid access to effective treatment for those who are diagnosed. In 2016, a significant decrease in HIV diagnoses in sexual health clinics in London has been attributed partly to gay and bisexual men at high risk of HIV infection buying PrEP themselves, before the IMPACT Trial.⁶³ England’s largest sexual health clinic, 56 Dean Street, in Soho, saw a 40% decline in new diagnoses in 2016. The clinic attributes the decline in part to PrEP but ‘not just PrEP’, with other factors such as rapid initiation of treatment, prescribing of PEP (post-exposure prophylaxis, a treatment that can stop an HIV infection after the virus has entered a person’s body) and the Dean Street Express testing service. We also know that globally, cities where PrEP is available are seeing more rapid falls in HIV incidence than cities that are not providing PrEP. As part of combination prevention, PrEP offers the opportunity to accelerate population declines in HIV incidence.



Health Equity Considerations

- The IMPACT Trial made PrEP available for men who have sex with men, trans men and women, people who are HIV negative and have HIV positive partners and heterosexual people considered at high risk of HIV acquisition. Access and awareness beyond gay and bisexual men remains extremely limited, places reserved for non-GBM had really low take up.
- PrEP available only in level 3 sexual health clinics risks widening health inequalities – these services are simply underused by women, BAME communities and trans people. To reach all communities, PrEP needs to be available in GP surgeries, maternity units, termination of pregnancy services, gender clinics and pharmacies.



Stigma Considerations

- PrEP can contribute to stigma reduction by allowing all individuals to be part of HIV neutral continuum of care.
- Misconceptions that HIV only affects particular communities may mean that at risk people don’t access PrEP or know about how to access it. Language often suggests that PrEP is only for those at “very high risk” of infection.
- PrEP’s availability only in level 3 sexual health clinics, therefore separating the drug off from other NHS services, risks reaffirming stigma with communities less likely to access clinics. Other prevention drugs like the pill or statins are available in a wide variety of NHS settings.

⁶³<https://www.aidsmap.com/news/dec-2016/uks-largest-sexual-health-clinic-saw-40-drop-new-hiv-infections-year>



ACTION 12

There must be clear financial accountability and responsibility for PrEP provision beyond sexual health clinics (for example, in GP surgeries, maternity units, gender clinics and pharmacies). This should include promotion to improve awareness and uptake for all communities who will benefit from PrEP.

It is clear from the evidence we collected, that while it is common sense to invest in prevention, to prevent larger care costs down the line while improving lives, there is a lack of clear, specific data that justifies this. This hinders funding bids at every level, as organisations are unable to provide figures to support appeals for resources. As an HIV commission, we have come across this same difficulty. A combination of methods is needed to address the dynamic needs of individuals. Understanding the return of investment of combination HIV prevention is fundamental to assess value for money, a key piece of information in the development of local and national budgets. Trying to understand what the full scope of this investment is, remains a key challenge that needs to be addressed.

While the cost of treating HIV remains high, financial efficiency could be improved by optimising the use of generic (non-branded) medication for treatment and prevention to mitigate the lifelong costs of HIV treatment and PrEP. Earlier implementation of generics as they become available offers the potential to maximise the scale of financial savings.⁶⁴

“We do not have adequate return on investment data for HIV interventions, and we do not know what constitutes an acceptable level of return on investment from preventing onward HIV transmission for different prevention efforts. This greatly stifles the ability to have clear economic deliberations when it comes to why investment in HIV prevention is so vital.”

Terrence Higgins Trust

New biomedical prevention technologies, including vaccines, different formulations and methods of delivery of PrEP and antiretroviral medications (such as via long-acting injection or implant) are in development and likely to be licensed before 2030 and important further tools in our shared aim to end new transmissions.

⁶⁴KJ Ong, AJ van Hoek RJ Harris J Figueroa L Waters C Chau S Croxford P Kirwan A Brown MJ Postma, “HIV care cost in England: a cross-sectional analysis of antiretroviral treatment and the impact of generic introduction.” (HIV Medicine) 20, no.6 (2019).





ACTION 13

The Department of Health and Social Care should develop a return on investment tool for HIV prevention interventions.

Starting this academic year, sex and relationships education (SRE) will become a mandatory requirement for all secondary schools in England. Guidance includes that pupils should know about STIs, including HIV, safer sex, and the importance of and facts about testing. This includes that 'effective teaching should aim to reduced stigma attached to health issues, in particular those to do with mental well-being'. We welcome this change towards mandatory SRE in all schools. The Sex Education Forum told us that in 2018, over a third of young people they surveyed had either learnt nothing about HIV in school or not learnt what they need to.⁶⁵ The move towards mandatory SRE was mentioned by stakeholders at multiple evidence hearings across the country. Particularly, many people proposed that teachers must be funded and supported to have proper training and up-to-date information about HIV to ensure that teaching tackles, rather than perpetuates, stigma. At our meeting in Manchester, it was suggested that community organisations might be well placed to deliver training in schools.⁶⁶

⁶⁵Sex Education Forum, Submission to the HIV Commission, January 2020.

⁶⁶HIV Commission Evidence Hearing, Manchester, February 2020.

LEADERSHIP

Make HIV a national and local priority, and set a desire for England to be the first country to end new transmissions.

HIV must be higher on the political agenda if we are to achieve our goal. The next 10 years present the country with an opportunity to beat this epidemic and make HIV a thing of the past. Our commission was born of a statement of leadership by the Health Secretary, Matt Hancock, in January 2019.

“Today we’re setting a new goal: eradicating HIV transmission in England by 2030. No new infections within the next decade. Becoming one of the first countries to reach the UN zero-infections target by 2030.”

Matt Hancock, January 2019

This statement of leadership prompted Terrence Higgins Trust, National AIDS Trust and the Elton John AIDS Foundation to establish an independent commission and invite us to investigate how to achieve this target. This report now must form a solid basis for the work of the government’s HIV Expert Group in informing the upcoming national Sexual Health Strategy and HIV Action Plan.

At evidence hearings, stakeholders told us that they felt HIV was politically on the backburner, and not getting enough focus in the press needed to change public attitudes. We heard that without better leadership from politicians and the media, the public would continue to associate HIV with contagion and death. The COVID-19 pandemic has shown us what the consequences of a stretched public service can be if a crisis hits. The HIV epidemic offers an opportunity to show how political leadership and commitment could create a public health success story.

We have already explored the multiple complexities in HIV care across England, which often means that multiple bodies and organisations share responsibility. While local leadership in some places convenes stakeholders, responsibility and leadership England-wide is lacking. The Fast Track City model seeks to combat HIV by ending urban epidemics by mobilising local political actors and stakeholders to achieve the 90-90-90 targets. At evidence hearings, we saw English Fast Track Cities at different stages in their journeys. Brighton and Hove was the first Fast Track City in England, and stakeholders all reported that the HIV sector all collaborated well, with strong leadership from the city council facilitating this. Manchester and Bristol both became Fast Track Cities in Autumn 2019, and in Bristol the steering group reconvened stakeholders for our evidence hearing.

“Being a part of the international Fast Track Cities Initiative has given us a real opportunity to learn from the rest of the world’s progress and start to disseminate our own learning and expertise to other partners.”

Brighton and Hove Fast Track Cities

Policy responses

As a country, we do not have nationally defined policy on HIV. There are recommendations, guidelines and aspirations around some components on the HIV continuum (for example, testing) but most decisions are made locally. In contrast, national-level strategies for prevention and management of HIV exist in all other nations of the United Kingdom⁶⁷

Following the implementation of the Health and Social Care Act 2012, having a strong policy foundation is more important than ever to achieve our 2030 targets. In particular, to provide clear guidelines on outstanding issues around commissioning, testing and delivery of HIV prevention interventions, including funding, responsibilities and accountabilities.

Fragmentation of the system has led to different parts not talking to each other meaning commissioning occurring in siloes or not happening at all (currently HIV support services and clinical nurse specialists do not have a commissioning home); HIV and sexual health clinical services no longer being located together which reduces access to important services, for example, screening.

In 2019, NHS England published their Long Term Plan outlining how £20.5 billion would be spent over 5 years. This did not make specific proposals for sexual and reproductive health but did indicate that there may be a greater role for government and NHS to play in the commissioning of sexual health services considering it is so closely linked to NHS care.

The NHS’ Five Year Forward View demanded a radical upgrade for prevention and public health that has not come into fruition. The Prevention Green Paper published in November 2018 outlined the government’s vision that ‘prevention is better than cure’.

While there are some clear challenges, there has also been some great progress in policy. In 2019, the government made a number of policy commitments on HIV; including ending new transmissions by 2030; to establish an expert group to develop an HIV Action Plan; to put in place routine commissioning of PrEP. Since September 2020 compulsory Sex and Relationships Education is being delivered in all schools, through which young people can be engaged on HIV prevention. Those successes should serve as the foundation for a nationally defined approach. Otherwise, we will continue to see variation in provision, creating a postcode lottery and exacerbating health inequalities.

⁶⁷KPMG, Ending the HIV Epidemic: An Assessment of HIV policy in Europe and recommendations to help improve the lives of those living with and at risk of HIV, 2019.



Health Equity Considerations

- Often tailored prevention services for key population groups – gay and bisexual men and BAME groups – are the casualty when services are cut back. Local authority spending on non-mandated sexual health, HIV prevention and testing in areas of high prevalence of HIV has decreased by nearly a third (29%) in the two years up to April 2017. Funding for targeted BAME sexual health promotion dropped by more than 50% in London.
- Key populations must be engaged more effectively in policy making and decision-making processes on both funding and services design.



Stigma Considerations

- A lack of understanding on what stigma is within policy making (as opposed to discrimination) makes agreeing on interventions and strategies to tackle it more difficult.

Political leadership

One of the key learnings of the commission is that sustained political leadership is an essential component of any efforts to end HIV transmissions. Having the commitment of the Secretary of State for Health and Social Care to end new HIV transmissions in England by 2030 has been a good example of that. This commitment has opened doors and facilitated stakeholder engagement across the system.

It is imperative that political leaders in the national and local arena continue to commit to ending new HIV transmissions. This will help coordinate efforts and allocate resources to achieve our common goals. They have the opportunity to develop and improve health systems, allocate budgets and prioritise HIV prevention.

At a local level, directors of public health, mayoral offices and local government associations have a key role to play. They share diverse responsibilities for health and have strong convening powers. Those can be used to provide leadership around HIV in their local areas.

National political leadership is fundamental – directly at Cabinet level, and at senior opposition level, and through the Health Select Committee to ensure that the government is held to account. Locally, elected members including cabinet members with responsibility for health, and councillors who have an interest in HIV (or are in high HIV incidence areas) are particularly important.

Lack of accountability or shifting of responsibility around HIV has been one of the biggest barriers to progress. We have witnessed examples of how “blame” has been apportioned to local government by national politicians, and vice versa. This does not help or improve our current systems and results in HIV not always seen as a local priority. There is a key need to raise up the agenda, especially in lower/middle prevalence areas as well as in some higher prevalence areas.



Health Equity Considerations

- It is important that political leaders acknowledge and act on the structural inequalities that lead some communities to be disproportionately affected by HIV.
- Communities most impacted by HIV must be better represented at leadership level across organisations and included in decision-making processes.



Stigma Considerations

- It is important – and can be assumed to have a positive impact – that political leaders publicly talk about HIV and engage in “busting myths”.

If we are to achieve our goal across the country, there must be overarching leadership from the top which commits to taking action to ending new transmissions across the country. Due to the complexity of the commissioning landscape of HIV and the shared responsibilities across the HIV continuum of care, it is imperative to have overarching oversight of the entire HIV response in England. In our written evidence, there is notable lack of reference to political leadership on a national level.

The government should not just continue to affirm its commitment to end new HIV transmissions by 2030 but should state its intention to be the first country to reach this goal and show new impetus with an aspiration to end 80% of transmissions by 2025. Progress on these goals should be reported to parliament annually.



ACTION 14

Accountability for meeting the 2030 goal should be shared by the Cabinet Office and the Department of Health and Social Care to drive the agenda. The minister must give an annual report to parliament on progress towards our goals – 80% by 2025, 100% by 2030 and England’s ability to be the first to end HIV domestic transmission.

We need access to the relevant information to hold the government accountable on this goal. Actions towards the 2030 goal must outlive political cycles, changing ministers and other emerging priorities. The experience of HIV from the very beginning has been that information and evidence, accessible to all, enables us to hold those responsible to account, welcome success and demand more progress. We think that having updated data on new HIV transmissions will be essential for this. Particularly, being able to compare data across populations will be essential to ensuring that we tackle inequalities as we make progress. Being able to visualise this data will be a powerful tool to bring transparency and accountability while measuring our progress against targets, prioritise resources, and assess areas for improvement.



ACTION 15

To ensure transparency, live granular data on progress towards our goal must be publicly available online in a simple format.

Justice system

In England, both reckless and intentional transmission of HIV are criminal offences.

A person may be found guilty of reckless transmission of HIV if it can be proved that they transmitted HIV to someone and they:

- Knew they had HIV
- Understood how HIV is transmitted
- Had sex with someone who didn't know they had HIV
- Had sex without using appropriate safeguards.

A person may be found guilty of intentional transmission of HIV (or attempted intentional transmission) if it can be shown that they actually and maliciously wanted to pass HIV on.

Many HIV advocacy organisations worldwide oppose the criminalisation of HIV transmission, highlighting that laws are often not informed by the latest scientific and medical knowledge relevant to HIV. The Global Commission on HIV and the Law in 2012 concluded that criminalisation is only justified in cases where transmission is both actual and intentional. Wider criminalisation, such as that of HIV non-disclosure and exposure, is “disproportionate and counterproductive to enhancing public health.”⁶⁸

Submissions to our commission noted that there is no evidence that criminalisation acts as a deterrent or reduces transmission. Instead, it undermines public health efforts and perpetuates stigma.⁶⁹

“If continued criminalisation results in just one person deciding against an HIV test, or one HIV service provider being unsure of the advice or support they should give, or adding to the burden of stigma already faced by people living with HIV, then the law needs urgent reconsideration.”

Carl Wonfor

⁶⁸The Global Commission on HIV and the Law, *Risks, Rights and Health*, 2012.

⁶⁹NAT, *Submission to the HIV Commission*, January 2020, Carl Wanfor, *Submission to the HIV Commission Have Your Say*, March 2020.

It is important that a wider review of the law on reckless and intentional transmission is undertaken, as recommended within the scoping consultation by the Law Commission of England and Wales.⁷⁰ Rather than supporting HIV prevention efforts, there are indications that fear of prosecution discourages people from testing for HIV, talking openly to their physicians or counsellors, or disclosing their HIV-positive status.⁷¹ Further, prosecutions for reckless HIV transmission unjustly target diagnosed HIV positive people for punishment and fail to reflect the broader shared responsibilities for sexual health and HIV infection.⁷²

It is clear to us that harm reduction approaches to public health, rather than criminalisation and prosecution, are the best and most effective way to prevent new cases of HIV and improve lives.

“Harm reduction interventions should be scaled up to mitigate HIV risks among injecting drug users.”

Release

Those in prison and immigration detention centres may be more likely to be living with HIV. It is therefore crucial that these populations have access to HIV testing, and that their HIV treatment is not interrupted by their incarceration.

Despite the fact that both types of incarcerated populations have a legal right to necessary health provision equivalent to that of those not in prison or immigration detention, evidence shows that access to testing and treatment can in reality be patchy and inconsistent. If we are to end new HIV transmissions, no one can be left behind in our response.



Health Equity Considerations

- People in prisons and immigration detention are entitled to equivalent healthcare to that available outside of detention but often this is not the case.



Stigma Considerations

- The criminalisation of ‘reckless’ transmission undermines public health efforts by perpetuating stigma while not reducing HIV transmissions. Investigations are often protracted and accompanied by stigmatising media coverage. The law encourages people to think that sharing HIV status is a duty.

⁷⁰Global Commission on HIV and the Law, Risks, Rights and Health, July 2012.

⁷¹United Nations, Ending overly broad criminalization of HIV non-disclosure, exposure and transmission, 2013.

⁷²National AIDS Trust, Why NAT opposes prosecutions for reckless HIV transmission, April 2020.





ACTION 16

The government must review and assess the impact of current policies and legislation which act as a barrier to HIV progress or where performance improvement is needed. This must involve reviewing laws that criminalise HIV transmission, expanding needle exchange programmes, and improving sexual health services (including opt-out testing) provided in prisons and immigration detention centres.

Local leadership

Local responsibility for public health forms the backbone of much of HIV care in England. Local councils make many of the decisions that determine the provision of services across the country. Our evidence hearings in five English cities highlighted both the strengths and weaknesses of this model. Where local authorities are proactive, work closely with community organisations and provide leadership, they form the core of an effective HIV response. Where the local authority commissioning is not carried out wisely, it has implications for the entire local response to HIV.

“In Herefordshire, a rural county, the main challenge is late HIV diagnoses. This is partially due to stigma attached to HIV infection and stigma in identifying as a man that has sex with men (MSM). For the same reason, stigma, there are periods of outbreaks of syphilis especially in MSM.”

Integrated Sexual Health Services for Herefordshire, Solutions 4 Health

Further to this, we often heard that where responses from urban areas are strong, neighbouring local authorities that serve more rural areas do not have the same provision. People served by rural local authorities often travel into cities for support and care. As HIV changes over the decade, success will be contingent on focused local action. This must go beyond places currently recognised as having high HIV prevalence, to areas where HIV has not traditionally been a priority, to ensure progress is equal across the country. Local government, the community sector, Fast Track Cities, and regional level bodies like Integrated Care Systems all have a role to play in this. Local authorities must plan and coordinate these local efforts to end new HIV transmissions.



ACTION 17

Local authorities should each develop their own local plan on how they will contribute to the recommendations of the HIV Commission, to ensure the 2025 and 2030 goals **are met**.

PARTNERSHIPS

Strengthen alliances within and beyond the HIV community.

The HIV care pathway is not a simple one and partnerships and collaboration are key to ensuring that it is possible to navigate a complicated system. We heard that in many instances, because budgets are limited, services operated in siloes or did not have capacity to collaborate, which led to waste and poorer care. As our healthcare system is increasingly organised around 'patient focused' care, it is essential that the system is easy to navigate, including between clinical and non-clinical needs. HIV is not the only long-term condition where this can be the case, and often people living with HIV experience less coordinated care because they are living with comorbidities which they are also managing.

Partnerships

Most of the success achieved on HIV treatment and prevention in England, has been a result of strong partnerships. They have played a key role on accelerating the country's progress on HIV. The commission received a strong body of evidence of good practice including work among national and local government, community-based organisations, professional bodies, academia, private sector, activists and community members.

Partnerships and collaboration between stakeholders help to pool resources, share skills and experience, share best practice, ensure services are accessible and acceptable, ensure messaging is appropriate and effective, avoid competing for campaign space and prevent disjointed pathways along which the most vulnerable often are lost.

We also know partnerships do not come without challenges and there is not a single formula applicable to all. Each partnership should look into what works and what needs should be addressed. But even then, challenges remain. For example, HIV service providers including community organisations and charities operate in a competitive environment bidding against each other during the commissioning of services. In a landscape of reducing funds, this creates barriers for cooperation among organisations.

When national, regional and local level partnerships are not coordinated, there is a risk of conflicting priorities or duplication of efforts and resources. More generally, differing cultures, goals and priorities between stakeholders can hinder effective partnerships. So it is important to build strong leadership, commitment, respect, shared visions and pool resources to overcome those challenges.



Health Equity Considerations

- Partnerships, co-design and leadership opportunities with community-led organisations, are essential to tackling inequalities.
- Those working in rural areas must be included as partners to ensure that we have a response appropriate to all areas and gains made in larger cities can be shared by others.



Stigma Considerations

- Partnerships beyond the HIV community have a huge role to play in tackling stigma.
- There are well-established partnership networks with some key populations (for example, gay and bisexual men) but not all key populations for HIV have these networks. Developing partnerships requires building capacity first.

Integration of care

“Poor integration of care can result in delayed or poorly-informed clinical decisions. People living with HIV lose confidence in the healthcare system and disengage. Some have died as a result.”

National AIDS Trust

HIV prevention and care is commissioned by multiple bodies and provided by national and local public, voluntary and private sector organisations. This can lead to a fragmentation of services, patients who are lost from the system when they fall out of contact and therefore do not get the healthcare they need, and the duplication of efforts. Addressing this will be even more crucial as the system manages national level changes to public health bodies and the related implications of this.

“Our experience is that the pathways between primary, secondary and community based care need to be further developed and strengthened. Far too many people ‘fall through the net’. They remain disconnected, unwell and isolated, and ultimately have poorer health outcomes and early deaths.”

The Food Chain

Commissioning

In 2012, the Health and Social Care Act changed the structure of healthcare in England. The Act separated treatment and care from prevention and public health. Responsibility for local public health services was passed to local authorities and Public Health England was created as a national body.⁷³ Most aspects of HIV prevention have been commissioned by local authorities since.⁷⁴ This includes those prevention interventions provided within sexual health services – both clinics and online provision is now split across multiple organisations. Local NHS clinical commissioning groups (CCGs) pay for HIV testing in primary care (for example, in GPs) and in secondary care (for example, in A&E or antenatal testing). Public Health England commissions the national HIV Prevention England programme, and the national home sampling programme that aim to complement local prevention efforts. NHS England (the national body) is responsible for commissioning HIV treatment services. Responsibility for HIV support services (which are non-clinical interventions) are locally determined.

The fragmentation of commissioning remains a significant obstacle to more effective joined-up HIV services and has become more visible over recent years. Successive cuts to the ring-fenced public health grant has led to a 25% reduction in local authority spending on sexual health services (including HIV prevention services) between 2013/14 and 2017/18, within the context of increasing demand for some services. Cuts and changes to one body have knock on impacts for others. Changes to social support services have resulted in increased pressure on HIV treatment services to provide support with social care issues. The impact of changes to service models or the retendering of part of a service where HIV and sexual health services are integrated and share a specialised workforce, causes destabilisation of wider services, fragmentation and increased costs.

When there are disagreements on who is responsible for aspects of the HIV pathway, the impact can be serious reductions in access. An example is PrEP, where a lack of agreement on who was responsible for its commissioning resulted in National AIDS Trust taking the issue to the High Court.

With regards to HIV prevention (and broader sexual health), there is an increasing movement (supported by the Department of Health and Social Care and Public Health England) for collaborative commissioning between local authorities and NHS organisations.⁷⁵ All of these organisations with responsibility for commissioning aspects of the “HIV pathway” will need to play a key role in achieving the 2030 goals.

⁷³Public Health England, *Making It Work: a guide to whole system commissioning for sexual health, reproductive health and HIV*, 2015.

⁷⁴Local Government Association, *Sexual Health Commissioning in Local Government*, 2019

⁷⁵1. Public Health England. *Making it work: a guide to whole system commissioning for sexual health, reproductive health and HIV*. [Online] 2015.



Health Equity Considerations

- Urban settings offer more HIV clinics and other services, which is linked to higher prevalence levels, meaning people in rural areas have to travel further for care.



Stigma Considerations

- Commissioners sometimes do not consider or understand that many people living with HIV are reluctant to access generic support services where they may face stigma.

Managing complex needs

Increasingly the health and social care system in the UK is intended to focus on 'person-centred' care – a holistic approach where an individual's care is organised in an integrated way, with each element of care delivered with thought to a person's wider needs. Person-centred care puts the patient first and developing systems that can support it requires patient involvement and co-design. It is especially important for people who experience a number of healthcare needs – 'multi-morbidity' or 'comorbidity' – where, historically, care for each health condition has been planned in isolation. Those who have complex needs (medical and non-medical) are more likely to be impacted by lack of integration. Poorly integrated care can cause inconvenience and unnecessary costs, but also risks clinically poor outcomes or even potentially dangerous treatment. The solution involves healthcare based on integrated provision that is well coordinated between different healthcare providers. As the cohort of people living with HIV in the UK is ageing, multi-morbidity is increasingly an important matter in managing their treatment and care.

People living with HIV tend to experience multi-morbidity at an earlier age than the general population. Distinct from the impact of ageing, for some people living with HIV the presence of non-clinical complexity, including factors such as use of social care, poverty, insecure housing, or migrant status, can also affect treatment and care needs. Difficulties in having to manage multiple appointments, with multiple consultants and providers, means that attending health appointments becomes expensive and all-consuming. Uncertainty over clinical responsibility undermines patient confidence in care. Inconsistent, sometimes contradictory, advice and treatment decisions lead to a lack of confidence in medical opinion. Having multiple tests, especially blood tests, sometimes being repeated only a few days apart, is frustrating and wasteful.



ACTION 18

NHS England and local authorities, working with the Department of Health and Social Care and its 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.

Care pathways for people living with HIV are often fragmented, affecting care for all but particularly for those with complex needs. HIV services are often unable to refer patients onto other services or referrals are not smooth, which means people are lost to follow up.

“Being able to cross-refer to other services, for example domestic violence, drug and alcohol, or even better, to work alongside these services to give wrap-around support when requested by the service user would also allow less scary and more positive conversations regarding how to make lifestyle changes as well as reducing duplication of services.”

Mary

People’s experience of living with HIV often intersects with their other needs. We know that the HIV epidemic does not exist in isolation and recognise that tackling other STIs and blood borne viruses is key to reaching our goal. Particularly in Birmingham, multiple stakeholders highlighted that hepatitis was a big issue in the city and that combined testing initiatives were necessary to tackle the two epidemics.⁷⁶ We heard that testing is incredibly fragmented and happens in silos, leading to duplication or missed opportunities. We agree that pairing HIV testing with other tests is not only practical but would serve to normalise HIV testing. Recent work in Merseyside, where testing services run by Liverpool University Hospital NHS Foundation Trust tested 400 people in temporary housing (housed during the pandemic) has led to 60 people being put on treatment plans for HIV and hepatitis C.⁷⁷

Partnerships working is often strongest in the community sector, where organisations build off each other’s expertise to reach new audiences and share best practice. We saw many great examples of partnership working, including in Manchester where we were hosted by the PaSH partnership; an alliance between The George House Trust, LGBT Foundation and BHA For Equality who work together on local health campaigning. The Fast Track Cities initiatives provided a space for partnership building across the sector in many cities we visited, bringing together community organisations, sexual health services, local government leadership and NHS bodies around a common goal.

It is clear that further collaboration is necessary across public health services to ensure that people do not fall through the gaps. Clinicians, support services and people living with HIV all expressed that there is a need for better collaboration with other public health services and community organisations, including but not exclusive to drug and alcohol services, mental health services and domestic violence services. This is to ensure clear referral pathways and shared knowledge.

⁷⁶HIV Commission Evidence Hearing, Birmingham, March 2020.

⁷⁷<https://www.itv.com/news/granada/2020-08-18/67-homeless-people-in-merseyside-now-on-hiv-and-hepatitis-c-treatment-plans>



ACTION 19

Commissioners should work with local providers and community organisations to ensure better co-delivery between drug and alcohol services (including sensitivity to the specificity of chemsex), domestic violence, mental health and sexual health services.

Mental health

Compared with the general population, people living with HIV are twice as likely to have a mental health issue.⁷⁸ While not everyone living with HIV will experience mental health issues within their lifetime, there is clear evidence to show that mental health and HIV are closely interrelated and that in order to treat HIV effectively you cannot ignore a person's mental health. However, 40% of HIV clinics do not have access to a psychological or mental health professional within their multidisciplinary teams (MDTs).⁷⁹ In the past HIV support services have provided psychosocial support for people who are newly diagnosed or struggling to cope with their HIV diagnosis. Many of these services have been decommissioned leaving people no choice but to access generic services for their mental health needs associated with HIV diagnosis. These services are simply not as effective for people with HIV. We know that stigma around HIV is still very much alive and severely impacts on a person's wellbeing and mental health and in extreme cases have even resulted in suicide.

Mental health support is proven to increase adherence to HIV medication by 83% in people with depression. Despite the clear public health benefits to treating mental health issues in people with HIV, it is generally not until people reach the more severe end of the mental health spectrum that specialised HIV services that support good mental health are provided.

The commissioning landscape for HIV and mental health is extremely complex because they are two separate conditions with different commissioning arrangements and pathways. While the government is committed to parity of esteem between physical and mental health, there is a lack of understanding of why generic services can often not meet the needs of people living with HIV.

⁷⁸Positive Voices Survey 2018, 'Changing Perceptions: Talking about HIV and our needs'.

⁷⁹The APPG on HIV/AIDS, *The Missing Link: HIV and Sexual Health*, 2020.



Health Equity Considerations

- Young people who have acquired HIV from birth are particularly susceptible to worse mental health for a number of reasons. There is concern that as adolescents are moved into adult services where there is less specialised care, they are particularly vulnerable.
- Benefit reviews are leading to suicides in people with HIV as a direct result of assessors not understanding the psychological effects of stigma, mental health issues and HIV.
- People with chemsex addictions are falling through commissioning gaps as drug and alcohol services are commissioned by local authorities but do not necessarily treat specific chemsex drugs or associated mental health issues.



Stigma Considerations

- Societal and self-stigma has implications for the mental health and wellbeing of people living with HIV.
- Stigma and self-stigma prevent people living with HIV from wanting to access generic mental health services.

“There are additional issues now where HIV services have to refer to primary care for all other ongoing health issues which means that, for example, someone identified with depression which could be treated in the HIV services now has to go their GP who, on the whole, are not proactive in calling patients even after letters from the clinic, so we rely upon the patient having the motivation to go to their GP to treat their depression which, due to numerous circumstances (unable to get a timely appointment, difficult booking systems, being sent back to the HIV services) they may not do and this will not be picked up until the next HIV appointment or if the individual deteriorates. Therefore there is a lack of robust pathways to support this.”

Shaun Watson

Not only are pathways to mental health support unclear, but often generic mental health services are not equipped to support people living with HIV. People living with HIV who want to access services are concerned about stigma and confidentiality, and so often feel better supported in HIV specific services. The APPG on HIV and AIDS recently reported that the government’s commitment to parity of esteem between physical and mental health services has brought investment in generic mental health services, but this misses this nuance that people living with HIV want prioritisation of HIV specialist mental health support, not just to access generic services.⁸⁰

“When diagnosing HIV, it was felt that there was very poor support offered. Peer support or support from a counsellor or social worker should be on hand at the point of diagnosis where possible.”

Body Positive

The community sector plays a substantial role in supporting people living with HIV to navigate care and delivering prevention. This often goes unacknowledged or is not considered an important part of a care pathway. Provision of peer support – where support is provided by people living with HIV, for people living with HIV – is a key component of this, but provision is patchy as services often rely on commissioners funding support via community services. This is despite the fact that in 2018, 1 in 5 people living with HIV said that they had needed help dealing with isolation and loneliness in the last year.⁸¹ In Bristol, Brigstowe aims to have peer support available in clinic at everyone’s first appointment at the Brecon Unit in Southmeads Hospital. This gives an immediate link into support after clinical appointments. Currently, there is no clear commissioning home which assigns responsibility for providing such services, so it only occurs in some local instances. Provision must become consistent across the country.



ACTION 20

The Department of Health and Social Care should provide clarity on where commissioning and funding responsibilities for HIV mental health and peer support services sit, review funding and show leadership to improve service levels and user experience for people living with HIV.

⁸⁰ The APPG on HIV and AIDS, The Missing Link: HIV and Mental Health, 2020.

⁸¹ Positive Voices, Changing Perceptions: Talking About HIV and our Needs, November 2018.

CALL TO ACTION

Our twenty actions outline a clear path to ending new HIV transmissions. We must urgently make these changes if we are to meet our goal within the decade. Our recommendations set a clear course for an urgent national HIV Action Plan to end new transmissions by 2030. This ambition is grounded in evidence and is achievable. During the commission process, hundreds of people contributed to our work. Now we must all own these actions, ensure they are taken forward working together with strong national leadership, and become the first country globally to end new HIV transmissions.

APPENDIX 1

The Advisory Group

The Advisory Group is formed of topic experts representing different sectors in HIV treatment and prevention. This group includes representatives from academia, community members, community-based organisations, government and statutory bodies, medical practitioners and clinicians.

Advisers are collaborating to write a set of 28 Evidence Papers on relevant topics for consideration by the Commission. The 28 papers are structured by five themes outlined by the Commission and will contain the most up-to-date data and expertise on the landscape of HIV in England. The production of these Evidence Papers represents an unprecedented collation of expertise from across the HIV sector. Once completed, the papers will be made public in the resources section of the HIV Commission website.

Members of the Advisory Group

More information about experts who supported the Commissioners can be found online: www.hivcommission.org.uk/advisory-group/.

Co-Chairs

Professor Kevin Fenton, Southwark Council, Public Health England
Matthew Hodson, NAM

Academics

Professor Caroline Sabin, Institute of Global Health & HPRU at University College London
Professor Catherine Mercer, Institute of Global Health & HPRU at University College London
Professor Peter Weatherburn, Sigma Research at the London School of Hygiene and Tropical Medicine
Professor Rusi Jaspal, Nottingham Trent University

Community-based organisations: Representation from organisations addressing the needs of most at-risk communities

Anne Aslett, The Elton John AIDS Foundation
Deborah Gold, National AIDS Trust

Denis Onyango, African Advocacy Foundation
Ian Green, Terrence Higgins Trust
Jo Josh, UK-CAB
Marion Wadibia, NAZ
Mark Santos, Positive East
Michelle Ross, cliniQ
Priscilla Nkwenti, the BHA for Equality
Rob Cookson, LGBT Foundation
Reverend Jide Macaulay, House of Rainbow
Salim Khalifa, Trade Sexual Health
Silvia Petretti, Positively UK
Simon Collins, i-base
Sophie Strachan, Sophia Forum
Will Nutland, Prepster

Government / Statutory: Representatives from national and local government and statutory organisations

Adam Winter, Public Health England
Andrea Duncan, Department of Health and Social Care
Janette Harper, NHS England
Jim McManus, Hertfordshire County Council
Jonathon O’Sullivan, Islington Council
Dr Jonty Heversedge, NHS England
Dr Laura Waters, NHS England
Professor Noel Gill, Public Health England
Paul Ogden, Local Government Association
Rob Coster, NHS England
Robert Carroll, Hampshire County Council
Dr Tristan Barber, NHS England
Dr Valerie Delpech, Public Health England

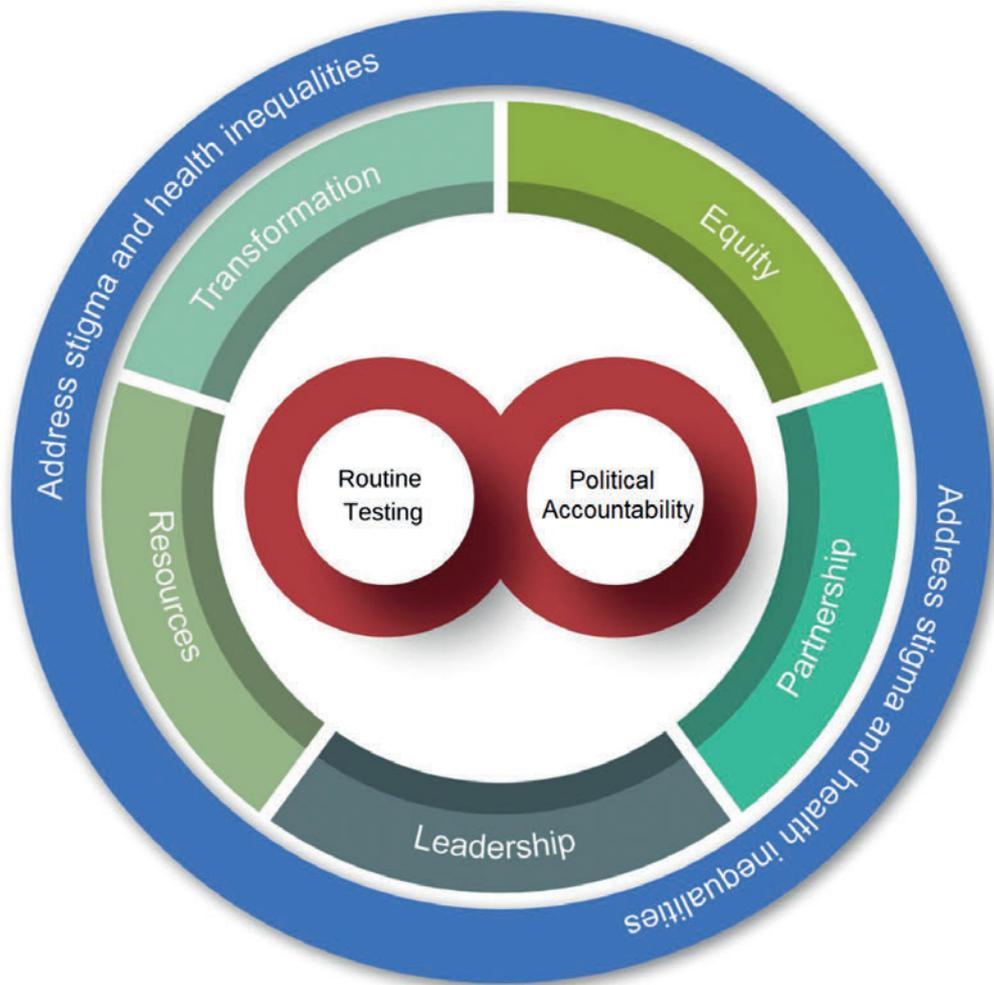
Medical practitioners / clinicians

Dr David Asboe, Chelsea and Westminster Hospital
Dr Kate Nambiar, Brighton and Sussex University Hospital
Dr Olwen Williams, BASSH

Supporting Members of the Advisory Group

The HIV Commission and the Advisory Group has received additional support, advice and guidance from the following organisations and individuals.

Abi Carter, Children’s HIV Association – CHIVA
Alice Welbourn, Salamander Trust
Dr Dan Baker, METRO Charity
Longret Kwardem and Rebecca Mbewe, 4M CIC
Meaghan Kall, Public Health England
Shema Tariq, Positively UK, UCL



TARGETS

By 2025: Reduce new HIV transmissions by 80%

By 2030: End new HIV transmissions

England : the first country to end new cases of HIV



hivcommission.org.uk



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