HIV COMMISSION

HOW ENGLAND WILL END NEW CASES OF HIV

The HIV Commission Final Report & Recommendations

EXECUTIVE SUMMARY

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.

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, and there needs to be equitable and easy access to this knowledge.

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

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 associate 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

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 strife, medical complications, living with stigma and discrimination. This is such a worthwhile aspiration, it requires urgent government action.

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.

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 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 units 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, with HIV testing across the health service.

OUR APPROACH

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.

HIV AND COVID-19

Coronavirus has exposed and exacerbated how structural inequalities linked to issues of poverty, race and immigration have implications for health. It has also brought multiple changes to the HIV landscape, with PrEP availability further delayed, many people organising their sex lives differently and an increased reluctance to access services as a result. Our recommendations consider these changes and include actions on how we can better react to change going forward.

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

By 2025: Reduce new HIV transmissions by 80%

By 2030: End new HIV transmissions

England: the first country to end new HIV transmissions

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**
	2,861	Under 900	Under 100
Gay and bisexual men	1,163	< 450	< 50
Heter. Contact – women	558	< 230	< 25
Heter. Contact – men	515	< 170	< 19
Black Africans	466	< 165	< 18
Deaths in England	**472**	**Under 95**	**Under 11**
AIDS at HIV diagnoses	**219**	**< 45**	**< 5**

*Based on data from Public Health England, 2020

Address 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 care sector has a responsibility to stop HIV stigma and address health inequalities throughout their work.

Stigma and health inequalities remain substantial barriers for people testing for HIV and accessing prevention and care. We know this is an endemic challenge across healthcare services. We must consider how our efforts address and avoid enhancing stigma and 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.

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 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.

Increasing the general population's knowledge and awareness of HIV prevention and treatment options will help address HIV stigma and encourage uptake of prevention methods. Anecdotally, we know that people living with HIV are concerned that knowledge of how coronavirus is transmitted may confuse or undermine already poor understanding of how HIV is transmitted. We must therefore double down on our efforts to improve public knowledge.

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.

TRANSFORMATION

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

Everyone should know their HIV status. Identifying HIV infections through testing is the first essential step towards prompt, effective treatment which both benefits individuals and prevents the onward transmission of infection.

HIV testing must become standard, like it has in maternity units. Midwifery services have almost completely eliminated 'vertical transmission' to children thanks to this approach. When patients register for a GP, present at A&E or 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.

Opportunities to identify undiagnosed HIV are limited because of current testing practices and the fragmentation of the system. This must change – quickly. In 2019, an estimated 5,900 people in England were living with undiagnosed HIV. As the number of undiagnosed HIV infections fall, the number of tests it takes to find an infection will continue to rise. As a result, the drive to normalise HIV testing must continue throughout the decade.

ACTION 4

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

The COVID-19 pandemic has had far-reaching consequences for our national healthcare system. It has disrupted prevention activities and care access and impacted data collection. However, these challenges have accelerated the adoption of innovations, including telehealth and digital approaches which enable care while physically distancing. In the past, it has taken too long to adopt new technologies, most clearly in the case of PrEP. Going forward, the sector must be more robust in adopting innovation, whilst considering digital exclusion and ensuring inequalities are not exacerbated. New technologies must be adopted as an addition to, not a replacement for, face-to-face services, or the most marginalised will be left behind.

ACTION 5

The health and 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.

As the numbers of undiagnosed HIV infections fall, strengthening the delivery of effective partner notification is essential. Learning from the COVID-19 pandemic and 'track and trace' has highlighted the importance of this approach.

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

Some communities are still disproportionately at risk of HIV and progress is not shared equally across those affected. Where we know why inequalities exist, we need to take action. Where we don't, we need to find out why and address this.

HIV surveillance in England is recognised globally as excellent. Our current HIV data collection systems have been at the core of measuring the impact of HIV in our country. As we move into a new phase of smaller numbers in new infections, there is a need to update the way we collect and report data. While HIV continues to disproportionately impact gay and bisexual men and Black African communities in England, other emerging groups are increasingly affected by HIV. We must better monitor how key populations change across the decade to inform interventions at a community level, considering ethnicity, region, age, gender and sexuality.

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 transmission in the last 5 years.

Health inequalities drive late HIV diagnoses, increasing the risk of serious clinical illness. Understanding the reasons for each late diagnosis is fundamental not only to preventing HIV-related deaths but to identifying missed opportunities and ways to improve the wider system.

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.

RESOURCES

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

We already have the prevention and treatment tools we need to end new HIV transmissions. We now need to use them effectively and consistently across the country.

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.

Our HIV and sexual health workforce is shrinking at a time when more people than ever are living with HIV. 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 and those enabling excellent care outcomes for a growing number of people living with HIV.

ACTION 10

The government 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.

The success of combination HIV prevention is the principal explanation for the fall in HIV transmission among gay and bisexual men in England. We need to translate this progress across all populations and regions of the country.

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).

The challenges around the commissioning of PrEP in England have highlighted the fragmentation in our sexual health landscape. A lack of accountability has delayed access to this key innovation, enhanced health inequalities and created tensions across commissioning bodies.

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.

As financial resources continue to be stretched, the importance of value for money and return on investment in HIV prevention needs to be better understood to inform commissioners' budget planning.

ACTION 13

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

LEADERSHIP

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

Without clear leadership at all levels, HIV falls off the agenda and responsibilities remain unclear. When everyone is accountable, no one is accountable.

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. This must be supported by meaningful political leadership from the top of government.

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.

HIV data is a critical component of ending new transmissions. 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.

Legal and policy frameworks are structural interventions that can facilitate or become barriers to effective HIV prevention and care activities. Progress in ending new HIV transmissions is contingent on addressing such barriers, which will require a change in related public health services and the criminal justice system.

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.

As HIV changes over the decade, success will be contingent on focused local action. This must go beyond places currently recognised as having high and very 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, working with neighbouring boroughs and regional partners where this strengthens their approach.

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 goal is met.

PARTNERSHIPS

Strengthen alliances within and beyond the HIV community

The HIV response is strongest in places where there are strong partnerships across and beyond the HIV sector. This needs to be consistent across the country.

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 lost to follow up 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.

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.

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.

Support services for people living with HIV currently do not have a clear commissioning home. Often, it is assumed that people living with HIV are comfortable accessing generic mental health and support services when stigma presents a barrier to this.

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.

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.

OUR COMMISSIONERS

The HIV Commission has drawn on the ideas and experience of people living with HIV, businesses, the voluntary sector and the public.

Dame Inga Beale (Chair)
British businesswoman and the former CEO of Lloyd's of London

Dr Rob Berkeley
Founder and Managing Editor at BlkOutUK.com

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

Rev Steve Chalke
British Baptist minister, Founder of the Oasis Charitable Trust

Joshua Graff
UK Country Manager & Vice President EMEA & LATAM at LinkedIn

Dr Richard Horton
Editor-In-Chief of The Lancet

Mercy Shibemba
HIV campaigner and winner of the inaugural Diana Award

Wes Streeting MP
Member of Parliament for Ilford North

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

Mehmuda Mian
Associate Director of the Lokahi Foundation

Gareth Thomas
HIV advocate and former Welsh rugby captain

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 online: **www.hivcommission.org.uk/advisory-group/**.

HIV COMMISSION

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NATIONAL AIDS TRUST
Securing rights
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Terrence Higgins Trust

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