



# Bold Ambitions

Creating a new era in HIV prevention, care and sexual health

Our Strategy 2016–2021 | 2017 Revision



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1. Foreword from Jonathan McShane, Chair of the Board of Trustees

Terrence Higgins Trust's new five-year strategy *Bold Ambitions* was launched in 2016 and was well received by funders, commissioners and most importantly by our beneficiaries. To ensure that the strategy is still relevant and fit for purpose in a rapidly changing external environment, we will be undertaking an annual review. As part of this refresh we will underline our commitment to innovation in HIV prevention and care services, and giving greater emphasis to sexual health services that we provide as an essential part of our work.



Our funders, donors and supporters give generously, and they expect us to make best use of the resources provided to support people living with HIV and in poor sexual health. To deliver on these expectations and those of the communities we serve, we have set out an ambitious agenda that will:

- contribute to the end of HIV transmissions and improve sexual health
- support people living with and affected by HIV and poor sexual health
- ensure that the voices of people affected by HIV are heard.

During the past 12 months we have made demonstrable progress in delivering our strategic objectives. This includes piloting the first nationwide HIV self testing initiative, successfully leading *National HIV Testing Week* in England, contributing to the sector's campaign to make Pre-exposure prophylaxis (PrEP) available on the NHS, opening a new HIV and sexual health training centre in Glasgow and launching two innovative research reports on sex and relationships education (SRE) and HIV and ageing.

As an independent organisation we will never step back from our responsibility to campaign and challenge for the rights and interests of those in poor sexual health and those living with or affected by HIV.

How we will do this is expressed in this document. We remain fully committed to working in partnership across the sector and with other organisations – both statutory and voluntary – as our vision of the eradication of HIV transmission and improving the sexual health of the nation cannot be achieved alone.

We could not achieve what we do without the support of, and donations from, individuals, trusts and companies. Our staff and volunteers care passionately for people who are living with and affected by HIV and impacted by poor sexual health, and during the lifetime of this strategy we will increase the involvement and engagement with our service users and supporters to ensure that their voices resonate in everything we do.

We will continue to build upon the successes of the past, and develop better and more effective partnerships with those in the sector who share our aim to deliver a better future for our beneficiaries.

## 2. Introduction from Ian Green, Chief Executive Officer

We are passionate about being the HIV and sexual health charity for life.

HIV continues to be one of the fastest-growing serious health conditions in the UK, with more than 6,000 new diagnoses estimated in 2015 and over 101,000 people living with the virus in the UK.

The black African heterosexual community and men who have sex with men (MSM) continue to bear a disproportionate burden of HIV, and for MSM this also applies to other sexual health conditions.

More than one in four people with HIV are now over the age of 50, which presents its own challenges.

There are still far too many people – an estimated one in seven – who are unaware of their status.

Britain also has some of the highest levels of sexually transmitted infections (STIs) in Europe with an unacceptably high prevalence of chlamydia, gonorrhoea and syphilis, particularly among MSM and young people. In the absence of mandatory sex education, young people are growing up without the knowledge they need to make informed decisions about their own sexual health.

It is within this context, however, that we truly are at a crossroads – with the end of the HIV epidemic within our grasp. We have a real potential to take advantage of new advances in diagnosis, prevention and treatment to eradicate HIV transmission, end the stigma and discrimination associated with HIV and – through targeted interventions – encourage individuals to take responsibility for their own sexual health.



We have seen tremendous progress in the treatment of HIV over the last 20 years. We believe that delivering new ways to diagnose and prevent HIV – and to normalise them – will have a profound effect on the eradication of the spread of the virus and its impact. We must ensure that the 'oppressive weight of complacency', as stated so clearly by the Executive Director of UNAIDS, does not prevent or undo decades of progress.

HIV is a complex condition, and while advances in treatment mean that people with HIV can live long and healthy lives, living longer with HIV presents unique challenges. Stigma, discrimination and economic hardship remain real issues for those with HIV-related ill health and disability.

Young people and MSM are disproportionately affected by STIs. Those aged between 16–24 have the highest rates of chlamydia, herpes and warts while syphilis and gonorrhoea rates in MSM have risen dramatically in recent years. Our response to this requires a co-ordinated approach to health improvement, prevention and rapid access for all to high quality testing and treatment services. The alarming increase in reports of antibiotic-resistant gonorrhoea in parts of the UK highlights the fact that we must work even harder to develop new programmes, activities and initiatives so that good sexual health is a reality for everyone.

In these straitened times we have seen the impact of cuts to services and public health activity on people's lives. We are also acutely aware of how financial hardship, stigma and discrimination can compromise an individual's ability to live well. Terrence Higgins Trust will continue to challenge and campaign to ensure the issues important to our service users and supporters remain high on the parliamentary, local government and media agendas.

## 3. Our vision, mission and values

Terrence Higgins Trust is at the forefront of the fight against HIV and improving the nation's sexual health. Our vision, mission and values are set out below.

### Our vision

A world where people with HIV live healthy lives free from prejudice and discrimination, and good sexual health is a right and reality for all.

### Our mission

- To end the transmission of HIV in the UK.
- To enable people to enjoy good sexual health.
- To empower and support people living with HIV to lead healthy lives.
- To amplify the voices of those affected by HIV across public and political arenas to eradicate stigma and discrimination.

### Our values

- **Ambitious:** We believe individuals, and communities, are a force for positive change. We drive ourselves, and others, to make things happen.
- **Honest:** We communicate clearly, taking responsibility for both successes and challenges. We are transparent and accountable to our communities, donors and funders.
- **Different:** We are radical professionals, proud of our diversity and united by a common cause. We support, respect and value each other and work without prejudice.
- **Independent:** We are an independent charity, rooted in the communities we serve. We use our voice to challenge and inspire change in health services, public policy and people's attitudes.



## 4. Background and context

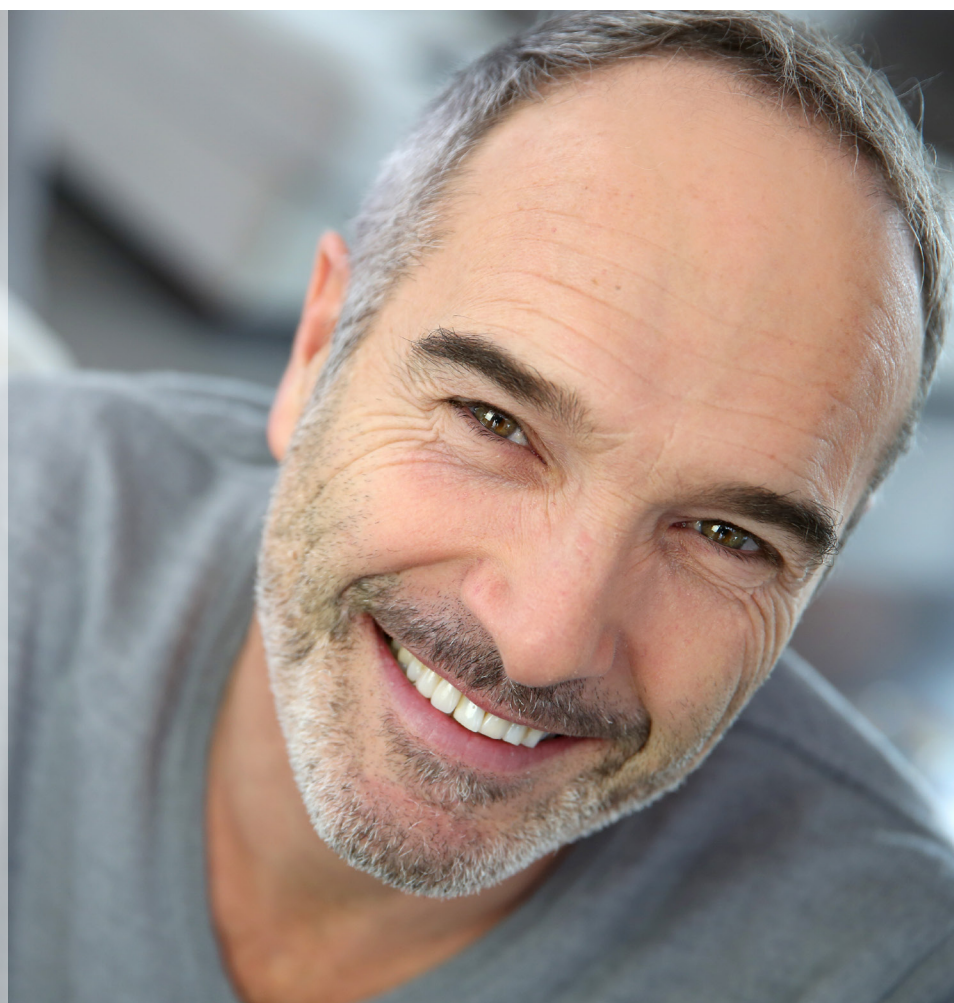
We are in a new era of HIV prevention, treatment and care where the need to improve the nation's sexual health has never been more pressing.

The 90-90-90 target set by UNAIDS aims by 2020 to diagnose 90% of all people living with HIV, provide antiretroviral therapy for 90% of those diagnosed, and achieve an undetectable viral load for 90% of those on treatment. In the UK we already exceed the second (96%) and third targets (94%); we currently fall short in the numbers of people diagnosed with HIV, with an estimated 13% undiagnosed according to the latest (2015) figures. We believe that in the UK we should aim to exceed, rather than merely meet, that target. But it is only with renewed political will, innovation and collaboration that we will do so.

Early diagnosis and immediate treatment are a powerful combination for reducing HIV incidence and improving the quality of life of people living with HIV. Treatment as Prevention (TasP) is increasingly the cornerstone of HIV prevention strategies around the world. The acceptance that people with a consistent undetectable viral load are not able to pass the virus on has led to greater priority being given to testing programmes to reduce the numbers of people with undiagnosed infection. Furthermore, the results of the international START study have demonstrated that early treatment is best for the long-term health of people living with HIV.

PrEP also provides a game-changing new strategy in preventing HIV infections. Several international studies have proven that PrEP is highly effective in preventing HIV, with the challenge now being to ensure that PrEP is available to all who would benefit from it.

**HIV continues to be a challenge for many, especially the long-term diagnosed and older people.**



Our response to HIV and sexual health in the next five years will be shaped by the funding restraints to both Local Authorities and national commissioning bodies. In England, Local Authority social care budgets do not currently cover the demands of an ageing population, and Local Authority public health budgets were cut in-year in 2015-16 by £200 million. Further reductions in the funding for public health are set to continue year-on-year until the local public health ring-fence is removed in 2018. Similar funding challenges are likely to be seen in Scotland and Wales. Scarcity of resources can bring with it innovation in the way services are delivered and the need to reinforce why services are essential, but where continued funding cuts are impacting on the lives of people living with HIV, action must be taken.

Since our last strategy was written, HIV treatments have continued to improve the lives of those living with HIV and also created new opportunities to end the transmission of HIV. HIV continues to be a challenge for many, especially the long-term diagnosed and older people.

HIV stigma is a major barrier to people taking up opportunities for testing and treatment. It continues to have a significant impact, especially on those who are still coming to terms with their diagnosis. Myths and misunderstandings around HIV continue to perpetuate stigma, and we need to better understand its impact on those affected, and the views of the general public.

Inequality in terms of sexual health is still a reality for many, and thousands of young people become needlessly infected with STIs every year because they begin their adult lives without the basic knowledge needed to maintain good sexual health.

In this new era of biomedical interventions, it is important to remember the people at the heart of our work and the personal services Terrence Higgins Trust provides. The way people communicate and engage with services has changed dramatically since the publication of our last five-year strategy in 2010. Digital technology has changed the way we communicate, form relationships, access services and meet sexual partners. As it has done throughout its history, Terrence Higgins Trust is now evolving to adapt to this new reality so we can provide information and services fit for the world we live in. Integrating face-to-face and digital services to provide choice, enabling more people to personalise and manage their own support needs, will become increasingly important.

Terrence Higgins Trust is ready to lead this new era in the fight against HIV and to assist in improving sexual health, and this document sets out how we will make it happen.

## 5. Our strategic goals and priorities for 2016-2021

### End HIV transmission and improve sexual health

Around 13% of people with HIV are currently undiagnosed. This group accounts for at least two-thirds of all HIV transmissions in England. People diagnosed late with HIV are at greater risk of avoidable morbidity and mortality.

Reducing the level of undiagnosed HIV requires a step change in the volume of HIV tests undertaken annually by those at greatest risk, and a step change in access to testing. It also requires a culture shift in communities most at risk of HIV so that regular and routine testing becomes a cultural norm.

PrEP is globally recognised as a highly effective way to prevent HIV transmission. Ensuring it is available to everyone who would benefit from it is essential to stopping HIV transmission.

Many in the UK still suffer from poor sexual health, with different groups being disproportionately affected. MSM and some minority ethnic communities are disproportionately affected by HIV. MSM (especially those living with HIV) are also the group most affected by syphilis, gonorrhoea and human papilloma virus (HPV), whereas young people are most affected by chlamydia.

To combat these trends, better education – as well as access to information and services – is desperately needed.

#### Our strategic priorities:

- Increase testing among populations with high rates of undiagnosed HIV.
- Ensure access to the most effective prevention tools and treatments for HIV and other STIs, including PrEP.
- Ensure that everyone has access to high quality HIV and sexual health information.
- Support health professionals to normalise HIV testing.
- Increase access to condoms, health promotion and behaviour change interventions and sexual health testing through new delivery models, both online and face-to-face.

#### We will do this by:

- Influencing decision-makers to ensure access to PrEP for those most in need.
- Campaigning for compulsory LGBT-inclusive, age-appropriate sex education in all schools.
- Providing high quality SRE in educational settings.
- Investing in digital innovation in testing and condom provision.
- Maintaining condom use as a primary prevention message.
- Testing 100,000 people for HIV per year by 2021.



#### Nancy

Nancy explains why she supports HIV testing campaigns:

*'HIV is a subject very close to my heart as, in my own family, I have experienced the impact it can have. Nowadays there is medication that helps control the virus and HIV positive people live better and longer lives. The earlier you know about your status, the better and healthier a life you will have.'*

*'HIV among Africans is not only a problem that affects people in Africa, it is also here. We need to get tested and know our status and avoid infecting future partners or unborn children. The only way to get ahead, live a healthier life and avoid infecting future partners is to get tested.'*

#### This will be achieved by:

- Terrence Higgins Trust investing funds to increase HIV testing in England, Scotland and Wales by piloting HIV home testing.
- Developing new models to make online testing and condom provision financially sustainable by 2021.
- Using new testing technologies to develop new models of face-to-face testing.
- Sharing our knowledge and expertise on new testing approaches by publishing journal articles to increase the evidence base, encourage innovation across the system and influence funding bodies.
- Supporting GP and primary care providers to deliver testing.
- Normalising HIV testing in all communities at risk of HIV and among the general public.



## Empower people to live well with HIV

There are now more than 101,000 people living with HIV in the UK and they can have vastly different experiences of living with the virus and vastly different needs.

Someone who was diagnosed in 2016 and has begun treatment with very few side effects has a very different experience of living with HIV to someone who was diagnosed before there was effective treatment. The latter may have lived through the real possibility of death and the side effects of highly toxic early treatment regimes. There are increasing numbers of older people living with HIV who face isolation, uncertainty about the future and economic hardship.

Terrence Higgins Trust seeks to ensure that everyone diagnosed with HIV, regardless of location and level of need, is supported to live well and thrive. This includes case management for people vulnerable to losing contact with HIV services, and should ensure full access to services for undocumented migrants.

The delivery of these services should be appropriate to the individual and their circumstances and be fit for the way we live now, including both digital and face-to-face services.

### Our strategic priorities:

- Provide tailored support for people living with HIV at key life stages and times of need.
- Provide an accessible core 'universal' support service across the UK.
- Support the health, wellbeing and financial resilience of people living with HIV.
- Connect people: online, face-to-face and through partnerships.
- Enable people to be as resilient as possible by accessing resources and support to live well and thrive.

### We will do this by:

- Establishing an innovative and accessible programme of services for people with HIV which is available to all, regardless of where they live in the UK.
- Developing and delivering services specifically addressing the needs of older people with HIV.
- Supporting primary care to be more involved in developing effective models of integrated HIV care which best meets the needs of people ageing with HIV.
- Fostering and developing local service innovation, sharing what works across Terrence Higgins Trust and its partner organisations.



### Mark\*

Mark explains why Terrence Higgins Trust's Health Wealth and Happiness project (which provides support and services to the over 50s who are living with HIV) has been a lifeline for him as he gets older.

Mark, who is 51, has been living with HIV for 30 years and accessing Health Wealth and Happiness for the last six months. He explains that the best part of the programme is: 'Feeling that I am not alone in my situation and circumstances, and that there are others I can reach out and relate to.'

Since joining the project Mark has learnt computer skills and attended regular yoga classes that help him with pain management. He also accesses counselling and coaching services that have helped him to set daily goals and move forward with his life.

Mark has struggled with his illness as he has got older – particularly with stigma. He felt like he was not a priority in the health system. Since discovering the Health Wealth and Happiness project he has felt hugely optimistic about his social and personal development.

\*Name has been changed to protect client confidentiality.

### Revolutionising services for people living with HIV by 2021 by:

- Undertaking a needs assessment of the current population diagnosed with HIV and the services currently available to them.
- Conducting a comprehensive audit of HIV support services to identify gaps and areas of efficiency and innovation.
- Re-designing HIV support services provided by Terrence Higgins Trust – to provide best value and to take full advantage of new technologies – based on the life-course of people living with HIV from new diagnosis and treatment to ageing and living well.
- Empowering people living with HIV to look after their sexual health.
- Supporting people living with HIV around substance misuse and other dependencies.
- Building a team of people living with HIV to speak at schools and colleges, talking about the realities of living with HIV today.

## Amplify the voices of people living with, and affected by, HIV

Central to our campaigning work are the voices of our service users and people affected by HIV and with poor sexual health. The principle ‘nothing about me without me’ is key. People living with and affected by HIV changed the face of public involvement in treatment in the 1980s and since then have been active in their own care and treatment.

We are learning lessons from the mental health sector, and our own, to inform best practice in ensuring people affected by HIV help us achieve the greatest impact for their benefit. With rates of HIV continuing to remain high, increased pressure on budgets and funding and increased competition for providing treatments and interventions on the NHS, it is vital that policy-makers, commissioners and others understand and meet the needs of those affected by HIV.

Parliamentarians in Westminster, the Scottish Parliament, the Welsh Assembly and the Northern Ireland Assembly play a key role in holding their governments to account. With the new commissioning landscape and devolution of powers, local decision-makers now make important decisions about prevention, health promotion, testing and social care and must be held accountable for them. This means that clear, evidence-based arguments must be communicated as to why HIV and sexual health-related priorities, such as sex education, are essential.

While the media can be an effective partner in supporting positive change, stereotypes and misinformation are less likely to prevail when the voices of people affected by HIV are heard, helping to eradicate stigma and discrimination.

### Our strategic priorities:

- Ensuring the early and meaningful involvement of service users, volunteers and those directly affected by HIV and sexual health issues in all our work.
- Putting the voices of Terrence Higgins Trust's service users and those directly affected by HIV and sexual health issues at the centre of our policy, media, campaigning and research.
- Working with people affected by HIV to ensure that HIV and sexual health has a visible place on the public health, social care and broader HIV policy agenda.
- Working with young people to ensure that LGBT-inclusive, age-appropriate sex education is compulsory in all schools.

### We will do this by:

- Reviewing our membership offer and engagement to establish new and innovative ways of ensuring that people affected by HIV can make the contributions they wish to make to our policy, campaigning and research work, and be partners in it.
- Challenging myths and negative media attitudes towards HIV and people living with HIV.
- Being a strong voice in our national parliaments and local decision-making forums to ensure HIV and sexual health remains high on their agendas.
- Using strong evidence, based on the experience of service users, make the case for why HIV and sexual health services are essential.
- Working with people affected by HIV to improve public perceptions and reduce levels of HIV-related stigma in affected communities.



### Alex

Alex Sparrowhawk, Terrence Higgins Trust's Membership and Involvement Officer.

*'People with HIV have been involved in their own care and services since the outbreak of the virus. This is embedded in the community's DNA.'*

*'Terrence Higgins Trust gave me the knowledge and confidence to share my personal story and become fully involved in campaigns that directly affect me as a person with HIV. I've witnessed first-hand MPs at parliamentary events, consultants during a BHIVA conference and journalists during media interviews putting themselves in my shoes as I've shared my journey with them.'*

*'We must ensure people living with and affected by HIV and poor sexual health are given a platform to assert their perspectives and be heard in their own right.'*

### This will be achieved by:

- Ensuring public awareness of the positive impact of treatment on transmission and helping people to live well with HIV.
- Working in partnership with other sector organisations to ensure our activities are well aligned demonstrating 'generous leadership' in our engagement with partners.
- Ensuring the media's portrayal of HIV is evidence-based, uses appropriate language and is informed by those living with the virus.



## 6. Sustainability, innovation and governance

We will diversify our funding and develop our brand to open new funding streams. We will work in partnership with other organisations and invest in our workforce to build on its capacity.

We will attract and retain the right people to deliver our strategy by:

- Ensuring Terrence Higgins Trust is a place where people want to work and volunteer.
- Encouraging our people to engage with our vision, mission and values.
- Developing confident and inspirational leaders who bring out the best in our staff.
- Nurturing and recognising the efforts of the people who work and volunteer with us.

Innovation is essential for the success of the organisation and is key to understanding the needs of our beneficiaries and helping policy-makers keep abreast of change. We will invest time to interact with our key stakeholders, beneficiaries and staff to make this a priority, seeking new ideas to improve the delivery of our services. We will continuously innovate to develop new services that meet the needs of our beneficiaries in cost-effective ways. We will invest in our digital infrastructure with a new website and online service platform due to be launched in the 2017/18 financial year.

Our governance processes will ensure that decisions are taken utilising the best possible information and will be characterised by transparency, robust challenge and ongoing evaluation and review.

For over 30 years, Terrence Higgins Trust has been at the forefront of the fight against HIV and for better sexual health. With medical advances and the power of new technologies, we now have the tools to end the HIV epidemic in the UK, transform the lives of those living with HIV and improve the sexual health of all. This strategy is our commitment to making these bold ambitions a reality.



## The HIV and sexual health charity for life

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