



**NATIONAL  
AIDS  
TRUST**

Securing rights  
Stopping HIV

September 2020

# **National AIDS Trust**

# **Strategic Plan**

# **2020 - 2025**



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# We are the National AIDS Trust.

Our vision is a world where HIV does not stand in the way of health, dignity and equality.

Our purpose is to stand alongside and defend the rights of everyone living with, affected by or at risk of HIV.

Our expertise, research and advocacy secure lasting change to the lives of people living with and at risk of HIV.

And we won't stop until everyone affected by HIV can live their fullest life possible.

Our strategic aims to 2025 are:

- **STOP:** we will stop new HIV infections
- **CHAMPION:** we will champion the needs of people whose voices and experiences are too often ignored
- **PROTECT:** we will protect the rights of everyone living with and at risk of HIV
- **DRIVE:** we will drive engagement and activism to change attitudes to HIV.

# How we got here

Since 1987 our work has kept HIV on the agenda, driving change, and improving the lives of people affected by HIV.

Our work is values-led and embedded in our community. We understand that HIV is much more than a health condition, so our approach to combatting its effects and stopping new transmissions is wide-ranging. Tying this work together is our belief that health is a human right. Our success relies on our expertise, our credibility, our independence, and our strong relationships with allies.

Our ambitious approach has achieved tangible results for over 30 years. These have included:

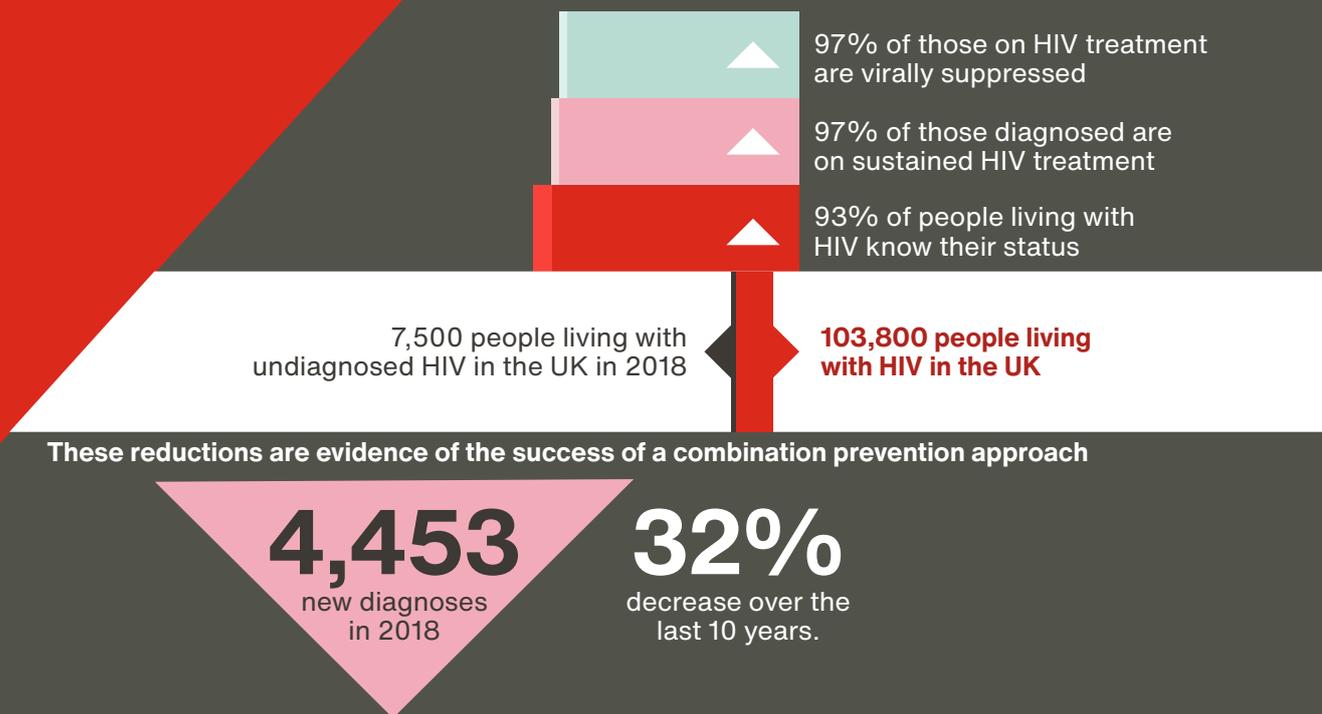
- securing access to PrEP, the life-changing HIV prevention medication, via successful litigation and ongoing advocacy work in collaboration with our allies
- increasing public support for and understanding of HIV through annual high-profile World AIDS Day campaigns
- driving home the impact of stigma and discrimination on people living with HIV through our activism and campaigning work and sharing their stories
- increasing legal rights for people living with HIV by securing its recognition as a disability, making pre-employment health questionnaires illegal, and most recently ensuring that social care employers around London stop this unethical practice.
- improving individual and public health by securing free access to HIV treatment, sexual health services, and primary drug and alcohol treatment regardless of immigration status
- using our expertise and convening power to develop consensus and use this to drive improvements in HIV prevention, treatment and care such as on treatment as prevention, the needs of heterosexual people, care coordination and long-term condition management
- making sure people living with HIV have access to a fair benefits assessment that understands their experiences
- challenging discrimination in the financial services industry and increasing access to insurance for people living with HIV as a result
- protecting the rights of people in places of detention to HIV testing and treatment.

# The changing HIV landscape

We can stop new HIV infections with the right leadership, resources, and focus.

We are at a tipping point in progress towards the UNAIDS target of ending new HIV transmissions by 2030. A loss of attention could lead to a resurgence of the epidemic. We must take action now to avoid missing this chance.

Over the last few years the number of new diagnoses of HIV and the actual incidence of HIV has been steadily decreasing.

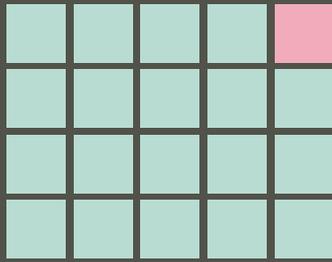


Data in this section from the following sources:

- O'Halloran C, Sun S, Nash S, Brown A, Croxford S, Connor N, Sullivan AK, Delpech V, Gill ON. *HIV in the United Kingdom: Towards Zero 2030. 2019 report*. December 2019, Public Health England, London.
- Auzenbergs M, Delpech V, Gold D, Kall M, Petretti S, Smithson K, Summersbey E. *Changing Perceptions: Talking about HIV and our needs*. November 2018, National AIDS Trust, Positively UK, Public Health England & Watipa, London.
- Auzenbergs M, Delpech V, Gold D, Kall M, Petretti S, Smithson K, Summersbey E. *Changing Perceptions: Talking about HIV and attitudes*. November 2018, National AIDS Trust, Positively UK, Public Health England & Watipa, London.
- <https://www.england.nhs.uk/commissioning/spec-services/npc-crg/blood-and-infection-group-f/f03/prep-trial-updates/>

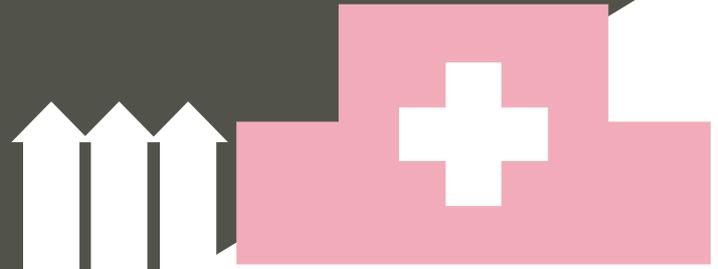
**PrEP**

Over 20,000 people accessing PrEP via the PrEP Impact Trial



4% women and other people at high risk

96% men and trans women who have sex with men



**1.1 million** HIV tests carried out in specialist sexual health services

**265,536** HIV tests carried out, sold or distributed in home and community settings

**Treatment and transmissibility**

78% of people start treatment within 91 days of an HIV diagnosis

13-15% of people living with HIV have transmissible levels of the virus

**The population of people living with HIV is growing older and many manage multiple health conditions.**

By 2023 over half of people living with HIV will be over 50. Health services for people living with HIV are fragmented with commissioners including Public Health England, local government, NHS England and Clinical Commissioning Groups, and providers including sexual health clinics, HIV services, GPs and voluntary sector organisations. This can make coordination or care difficult and negatively impact quality of life for people living with HIV, who are more likely than the general population to be managing multiple health conditions.

**Managing multiple health conditions**

73% of people living with HIV have at least one other condition

- 29% high cholesterol
- 23% hypertension
- 7% diabetes
- 12% arthritis
- 8% peripheral neuropathy
- 5% kidney disease

**Mental health**

50% of people living with HIV have at least one diagnosed mental health condition

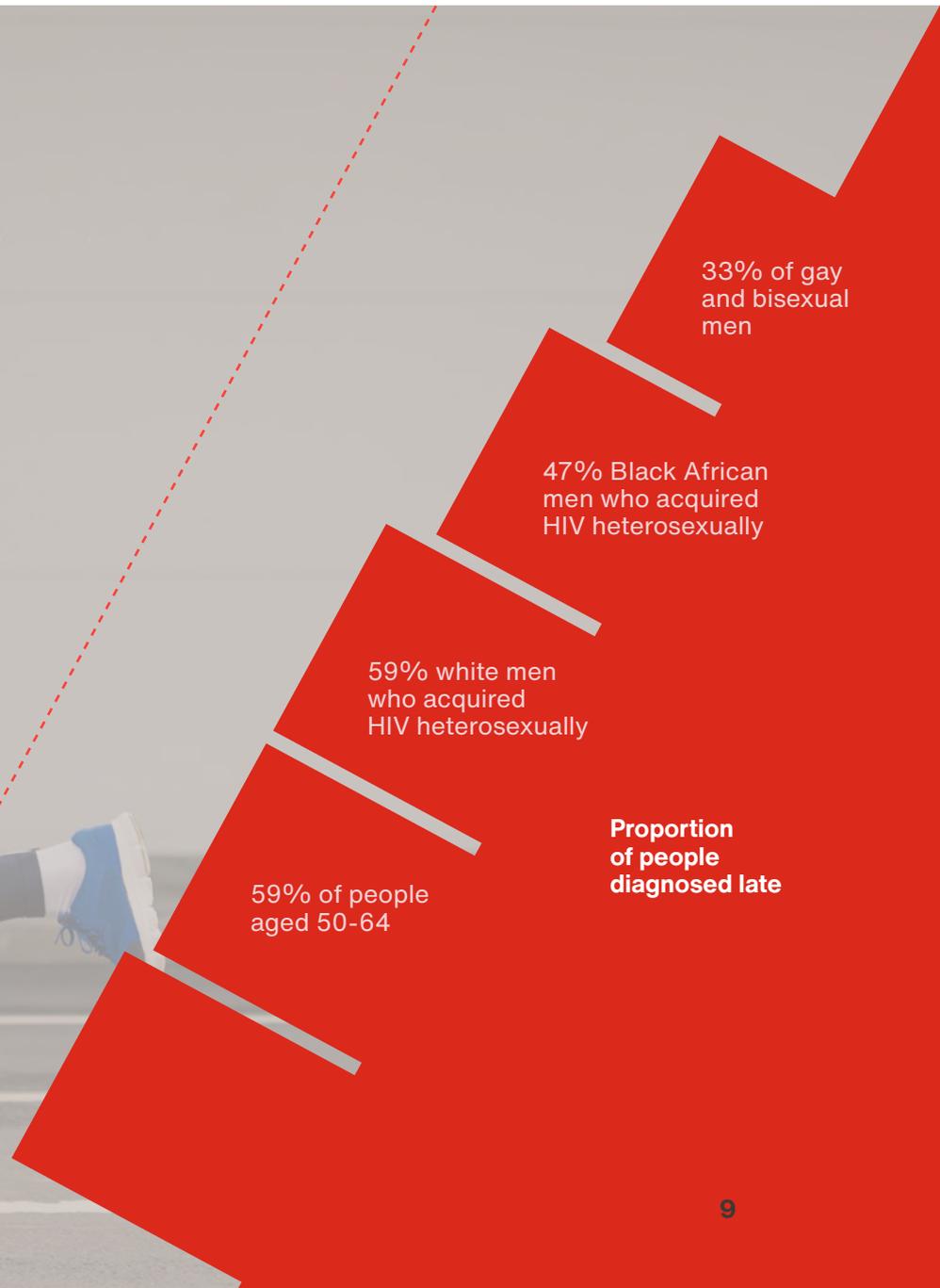
Double the rate in the general public

## Progress is unequal with some groups faring consistently worse than others.

Though the UK has made enormous strides in both preventing and treating HIV, this progress is not experienced equally. Those groups already most likely to experience structural discrimination are also most likely to be progressing at the same rate, and therefore need the greatest focus if we hope to achieve equity.

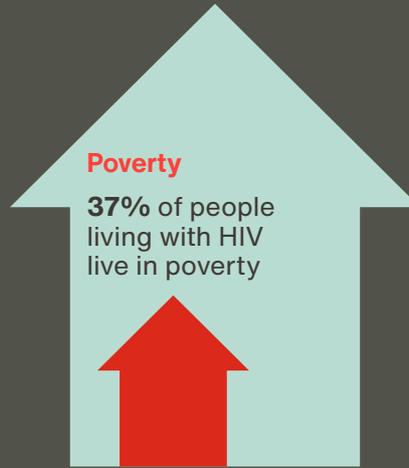
While the drop in new diagnoses has affected all groups, the decrease among gay and bisexual men is much steeper than for other groups. This includes those who acquired HIV via heterosexual sex. It is also much steeper for white gay and bisexual men than for those of other ethnicities.

Late diagnosis of HIV is the most important predictor for ill health and death for people living with HIV. Overall, while the proportion of people diagnosed late with HIV has decreased over the last decade; it remains stubbornly high at 43%.



## People living with HIV face additional challenges including stigma and discrimination.

Many people living with HIV do not find that HIV causes any additional problems for their lives. However, significant minorities struggle with a range of issues which impact on their quality of life, and support to meet these needs is not always available.



### Recreational drugs

23% of people living with HIV and 40% of gay and bisexual men living with HIV use recreational drugs compared with 9% of the public

### Support needs



1 in 5 people living with HIV report needing support with loneliness and isolation but **75%** did not get this support

Of **10,000** people needing peer support, **45%** did not get it.

### Discrimination within healthcare settings

11% of people living with HIV report being refused healthcare or delayed a treatment due to HIV status





# What we learned

To inform the development of our future vision and strategy we spoke to people inside and outside the organisation. We held discussion groups with people living with HIV. We listened to our Community Advisory Group. And we spoke to people across the sector including partners, stakeholders and funders.

## People told us our work is needed now, more than ever.

We learned:

### **We risk losing momentum.**

While we've made great progress there is so much more to do. Despite this, we struggle with the perception our work is done:

*'that AIDS and HIV have gone away'*

with a shared sense that

*'the real risk [is] of losing the battle, just as things are getting better'.*

While the external environment makes it harder to make the case for HIV, there is still a real need to make the case for funding HIV care and support – at national, devolved and regional government levels.

### **The HIV epidemic is changing, and quickly.**

As people living with HIV grow older, and manage multiple conditions, there will be new challenges.

*'But we don't just want people to live well with HIV – we want them to thrive!'*

Advances in treatment are improving and saving lives, and HIV testing and prevention remain a huge priority. Within a changing epidemic, and a constantly evolving health environment we will need to maintain a dual focus on maintaining HIV specialism where necessary while preparing mainstream services to support people living with HIV.



**We need to spread our influence and engagement to remain effective.**

Progress in fighting the epidemic is not shared equally among communities. We need to make sure we reach and engage with under-served populations, particularly tackling late diagnosis, access to PrEP and shared progress towards the UNAIDS 2030 elimination goals.

As more and more decisions on healthcare are taken at a local level, we must do more to reach into the NHS and local authorities to influence frontline practice.

We also need to understand the different experiences of people in different areas of the UK:

*'People outside the cities don't have access to support and are hugely isolated'.*

**Social circumstances and stigma have as big an impact as healthcare.**

People living with HIV disproportionately face barriers to their quality of life, including:

- increased homelessness
- poverty and food poverty
- barriers accessing benefits and support
- social isolation
- mental ill-health.

Success in combating HIV relies on challenging prejudices in all areas of life.

Stigma surrounding HIV was identified by many as one of the key challenges. This stigma comes in many forms – including internalised stigma and external stigma affecting every aspect of people's lives from accessing healthcare and financial services; to forming relationships and dating; to finding and keeping work; and within particular communities as well as the public.

Many stakeholders identified the need for collective action to find out how can we make sure we reduce HIV stigma for good.

## We found people had a clear idea of National AIDS Trust and our unique role.

People understand our unique position and clear focus as the leading organisation on HIV policy in the UK. They want us to stand up for people at risk and living with HIV, to represent them and act as a convener between Government, service providers and across the sector. People respect our brave approach and determination to deliver as well as our credibility and independence.

But they also recognised we need to shout louder and better respond to the changing environment. We need to reach outside the sector and across the UK to deliver effective change for people who need it most.

**Most importantly they were clear now is not the time to stop.**

**We must lead the fight for HIV rights.**

# Our Plan

## We will **STOP** new HIV infections.

Ending new HIV infections in the UK is for the first time a realistic and tangible goal.

We have a once in a lifetime opportunity to achieve this during a period when COVID-19 has improved public understanding of pandemics. However, standing in the way of reaching this goal is an underfunded public health system in which its different parts do not always coordinate well, a population undereducated about HIV, and disengaged politicians and decision makers. We will take action to remove these obstacles to progress, ensuring the UK maximises opportunities for innovation and take advantage of the tools we have, such as increased testing and access to PrEP.

**We will create the knowledge and political will needed to drive HIV prevention. We will do this by:**

- stewarding the independent HIV Commission (established jointly with Terrence Higgins Trust and Elton John AIDS Foundation) in its reporting of a 10-year plan to stop new HIV infection
- forming a consensus among stakeholders to support the commission's findings and deliver action
- influencing the Government's approach to ensure it reaches its goal of ending HIV transmission in England by 2030.

**We will ensure more people have the right access to prevention tools right for them. We will do this by:**

- fighting for uncapped access to PrEP for everyone who needs it
- pushing for increased momentum on HIV testing which will require the widest possible range of testing options and effective commissioning and delivery of programmes

- making the case for age-appropriate, LGBT-inclusive relationship and sex education, that includes up-to-date information about HIV risk, in all schools
- consistently focusing on reducing the factors contributing to late diagnosis.

**The COVID-19 pandemic has laid bare the impact of long-term chronic underfunding of public health in the UK. We will fight for a sustainably funded and well-functioning public health system. We will do this by:**

- working in collaboration with allies across the public health field to make a united case for investment in Spending Reviews
- responding to the proposed structural changes to the public health landscape, including ensuring national health protection activities are protected and prioritised
- making the case for equity of esteem between the NHS and the public health system
- influencing the Government to take action to improve accountability within the public health system.

# We will **CHAMPION** the needs of people whose voices and experiences are too often ignored.

Despite the UK's success in HIV prevention and treatment access, progress is not experienced equally by all those affected.

People living with, affected by or at risk of HIV come from diverse communities including their protected characteristic, location and experience. Structural inequality means the specific needs and experiences of these groups and individuals are not high enough on the HIV agenda. The impact of this failure is starkly demonstrated in the COVID-19 epidemic. Despite the challenges, the HIV community has demonstrated we have the tools to combat this – driving a shared understanding of the impact that blame, shame, stigma, personal responsibility and patient-led work can have in making progress. We will refocus the agenda to ensure we are meeting the needs of everyone with, affected by or at risk of HIV, wherever they are, whichever community they are from, large or small. We will ensure as we tackle the challenges ahead, no one gets left behind.

**We will stand up for those in smaller populations with significant unmet needs. We will do this by:**

- improving access to testing and treatment for those living in places of detention
- leading work to legalise drug consumption rooms, and improving harm reduction options for people who inject drugs
- working alongside trans allies to ensure services to meet the prevention, treatment and support needs of trans people living with HIV.

**We will use our voice and influence to add to the voices of people too often outside the main focus of HIV work. We will do this by:**

- shining a light on the needs of migrant communities and influencing decision makers to more effectively meet these needs
- ensuring a focus on women and HIV needs
- working alongside allies from Black, Asian, and minority ethnic communities to ensure their needs are understood and prioritised, including influencing the Government's response to COVID-19.

**We will represent every community affected by HIV. We will do this by:**

- speaking out against racism, xenophobia, homophobia, transphobia and misogyny, and making explicit the links between these, and HIV stigma
- increasing our involvement and engagement with people living with HIV from Black, Asian, minority ethnic, trans, and sex worker communities
- reaching out to and gathering evidence from people living with and at risk of HIV in all regions and nations of the UK.

# We will **PROTECT** the rights of everyone living with and at risk of HIV.

Access to healthcare, health equality, social justice, and a life free from stigma and discrimination are basic human rights.

**We will fight to ensure people living with HIV can realise these rights.**

**We will end HIV stigma. We will do this by:**

- leading work inside and outside the HIV sector to develop a national action plan for tackling HIV stigma in all areas of life
- making clear the links between HIV stigma and developing COVID-19 stigma
- ensuring everyone living with HIV can receive non-stigmatising health services
- fighting the injustice of criminalisation for reckless transmission of HIV, including by building new energy and consensus among the HIV community
- ending discrimination based on HIV status by challenging individual cases and supporting the sector to use the law to support individuals and change policy
- improving coverage of HIV in the media through a programme of positive engagement, and by challenging and correcting damaging stories
- playing our part in the international alliance of individuals and organisations sharing the Undetectable = Untransmittable message
- developing our digital resource to support people living with HIV to have evidence-based conversations about HIV.

**We will make health equality a reality for people living with HIV. We will do this by:**

- fighting for a health service fit for purpose, accessible to all, and able to cope with the changing needs of people living with HIV
- leading the HIV response to COVID-19, ensuring the health and social care system takes advantage

of new opportunities for service delivery, while protecting quality and access for everyone

- raising awareness of the needs and rights of people living with HIV with non-HIV-specific healthcare specialists, as people need a greater array of services and more and more services are delivered by mainstream services
- ensuring people living with HIV benefit from improvements made possible by the developing structure of the health system
- improving the NHS' ability to respond to HIV as a long-term condition
- defending the rights of people living with HIV to access the best and most appropriate medication and to live long and healthy lives
- focusing the health and social care system, including its developing structures, on the evolving needs of people living with HIV for the long term as they age.

**We will defend social justice for people living with HIV. We will do this by:**

- defending the support system for people living with HIV including activists, voluntary sector HIV organisations, and peer support networks
- ensuring people living with HIV have access to jobs and security, and financial services
- ensuring people living with HIV in poverty are not ignored
- ensuring people living with HIV get access to the right benefits and support.

# We will **DRIVE** engagement and activism to change attitudes to HIV.

We can't stop HIV harming people's lives on our own.

**We need a paradigm shift in public awareness of HIV, and support for people living with and affected by HIV. By working together with individuals and institutions we can drive engagement, influence and activism, and make real change happen.**

**We will encourage more people to support our fight for the rights of people living with HIV. We will do this by:**

- curating World AIDS Day campaigns that increase engagement and involvement, and can be used by organisations and individuals across the country and globally
- increasing knowledge of public attitudes and understanding of HIV by undertaking national polling
- engaging individuals nationally and locally help us make change happen via our HIV Activist Network
- publicising and disseminating the outcomes of the HIV Commission, in partnership with Terrence Higgins Trust and Elton John AIDS Foundation.

**We will work collaboratively with allies inside and outside the HIV sector, within and outside of the UK. We will do this by:**

- growing engagement with and support for our Policy Network
- making and growing our international alliances and learning, including through

delivery of our work to track European progress in tackling HIV and viral hepatitis

- exploring opportunities for launching new networks for clinicians and academics
- being active members of alliances to combat poverty, improve social care, improve harm reduction, and ensure access to healthcare for migrants and refugees.

**We will increase the meaningful involvement of people living with HIV in all our work. We will do this by:**

- growing our Community Advisory Group and increasing its integration with our work
- developing new ways of involving peer experts in the development of our programmes of work and in supporting the delivery of these projects.

**We will increase awareness of National AIDS Trust and our aims. We will do this by:**

- telling our story consistently and putting the rights of people affected by HIV at the heart of our work and messages.



# Will you join us?

Our success relies on your support. We have the potential over the next 5 years to make enormous strides in our work. Will you be part of our journey?

- Become a regular donor or make a one-off donation
- Join our HIV Activists Network
- Sign up to support our work
- Fundraise for us on World AIDS Day and throughout the year.

Find out more at [www.nat.org.uk](http://www.nat.org.uk).



**We're the UK's HIV rights charity. We work to stop HIV from standing in the way of health, dignity and equality, and to end new HIV transmissions.**

Aztec House, 397-405 Archway Road, London, N6 4EY  
T: +44 (0)20 7814 6767  
E: [info@nat.org.uk](mailto:info@nat.org.uk)

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No. 2175938, (registered in England and Wales)

Registered Office: Aztec House,  
397-405 Archway Road, London, N6 4EY

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