# **#ZEROHIV**

Our Strategic Plan 2019-2030



ZERO NEW HIV INFECTIONS ZERO **HIV-RELATED STIGMA OR** DISCRIMINATION ZERO **HIV-RELATED** DEATHS

## THIS IS OUR PLAN FOR SCOTLAND ....

An ambitious, forward-thinking plan that capitalises on our 25 years' experience at the centre of Scotland's HIV response.

We believe that by bringing together the right partners, working with a common goal, we can achieve zero new infections, zero HIV-related stigma and discrimination and zero HIV-related deaths by 2030. These three key targets form the basis of our Strategic Plan – everything that we do will work towards achieving these important goals.

Over the last few years, we've built our expertise as a trusted source of high-quality policy work, making recommendations to Government and Health Boards based on the views and experiences of people living with and at risk of HIV. This new phase of the organisation will focus on providing creative solutions to overcome sexual and drug related barriers to a healthier Scotland.

Our five pillars, outlined in this Strategic Plan, are the solid foundations for which our work will be developed. Over the next three years, we'll be working with everyone to bring about the right solutions to end the HIV epidemic in Scotland and share our experiences internationally to contribute on the global stage. These foundations, our 25 years' experience, and our creative solutions will help to achieve the best outcomes for a healthier Scotland.

Together, we can get to zero and ensure that Scotland is a healthier place regardless of HIV status. **So let's get to work, and get to zero.** 

Dr Nicoletta Policek Chair, HIV Scotland



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## FROM OUR CHIEF EXECUTIVE...

I'm incredibly proud to be leading this organisation into our 25th year, the year that HIV Scotland evolves from an organisation that doesn't just focus on problems – but one that aims to find solutions.

We are a living, breathing organisation that is agile and creative, holds itself accountable, and promotes equality while encouraging involvement from the real people we serve. Our small team will be looking for creative solutions to some of the key problems that stand in the way of reaching **#ZEROHIV**.

Publishing this document, our prospectus for a healthier Scotland, will help us build long and lasting partnerships. We hope that includes you. Getting to zero by 2030 is an ambitious task, and we can't do it alone. We hope that this vision, our plan for Scotland, inspires you to work with us and harness the power of our sector to reach **#ZEROHIV**. Our work continues to focus on getting the best outcomes for people living with and at risk of HIV. By focusing on our five pillars and moving away from talking about problems to solving them, we will forge a positive path to overcome sexual and drug related barriers to healthy lives in Scotland.

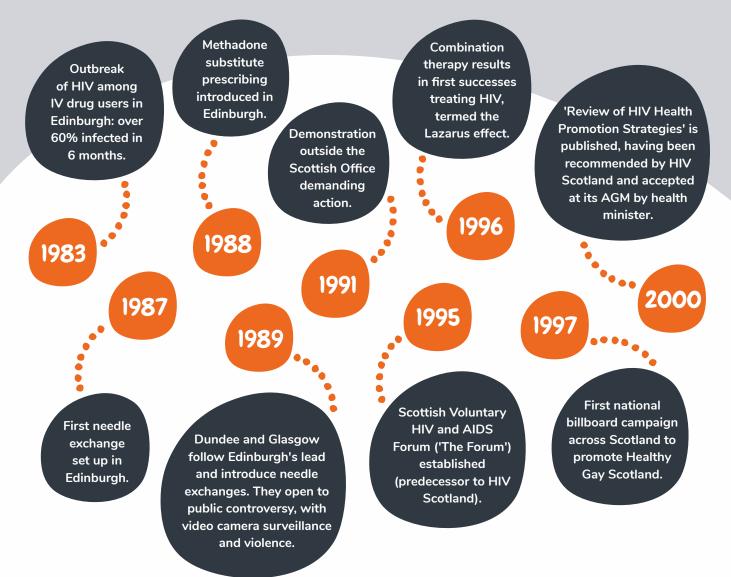
Join us on this mission and be the positive change our society needs.

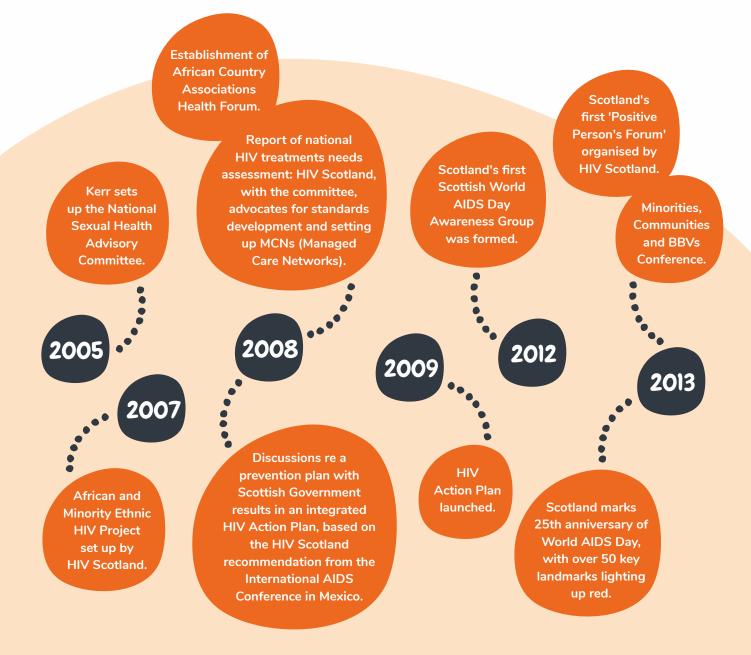
Nathan Sparling



## HISTORY AND ACHIEVEMENTS

HIV Scotland has played an important role in Scotland's response to HIV. As we enter our 25th year, and celebrate this key milestone, it is important to pause and reflect on our contribution and successes.









- https://www.hps.scot.nhs.uk/news/newsdetail.aspx?id=22844 on 17/01/2019.
- 2. Source: HPS (2018) Surveillance Report. HIV Infection in Scotland: Quarterly report to 30 September 2018. Glasgow
- 3. Source: HPS (2018) World AIDS Day: Scotland reaches WHO's 90-90-90 Target. Glasgow
- 4. HIV Scotland (2017) HIV Scotland's Survey on Student Sexual Health Education. Edinburgh

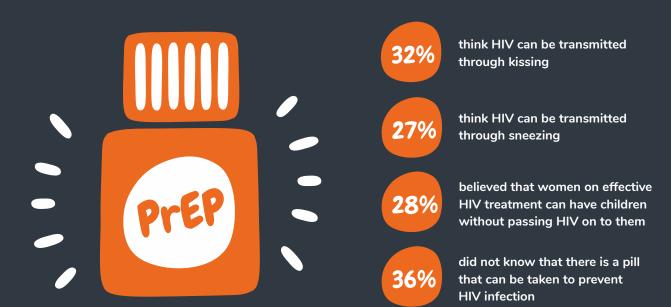
## **Our Voice Citizen's Panel** – Survey on HIV awareness, mental health and wellbeing and inclusive communication (Scottish Health Council)

If I found out I had an HIV positive status, I would know where to go for support

I would be comfortable starting a relationship with someone who is living with HIV

43% disagree or strongly disagree

disagree or strongly disagree



Source: Health Improvement Scotland (2018) Our Voice Citizen's Panel - Survey on HIV Awareness, Mental Health, and Wellbeing and inclusive communication. Glasgow

## EXPERIENCES OF STIGMA AND DISCRIMINATION

Participants worried primarily about sexual rejection (29%), being gossiped about (24%) and being excluded from social gatherings (19%) due to their HIV. A third (34%) had avoided sexual encounters in the last 12 months due to their status. One in seven had experienced sexual rejection in the last year due to their status, compared to a fifth of participants in the UK overall.

### MENTAL HEALTH AND WELL-BEING

**One in five** (22%) reported suicidal ideation in the last year, comparable to **18%** of the population in the UK overall.

#### HEALTHCARE

A third worried about being treated differently to other patients at their GP and dentist, while **18%** and **12%** had avoided care in either setting respectively. Similar trends were observed in outpatient and inpatient care. Eight people (**8%**) reported they were pressured by a healthcare worker to disclose their status to others in the last 12 months.

#### HIV AND THE LAW

**7%** (n=7) of participants in Scotland reported being denied insurance products (e.g. health, dental, life, or job protection) in the last year. Two people (**2%**) had been investigated by the police in relation to their HIV status. Only **16%** of participants in Scotland felt able to influence legal or rights matters affecting people living with HIV, yet **a third** (32%) had tried to address an issue of HIV-related stigma or discrimination within their community.

Overall, **91%** of participants were aware that people have been prosecuted for recklessly transmitting HIV to a sexual partner, and **one in five** (18%) believed that transmission of HIV should be a criminal offence; **half** (48%) were not sure. **Two in five** (42%) reported that the risk of criminal prosecution relating to HIV transmission has influenced decisions to tell others they are positive.

### SUPPORT AND ADVOCACY

**More than half** of participants in Scotland reported they had sought support. People living with HIV in Scotland thought action should be taken in the following areas:

- Education in schools: 65%
- Raising public awareness and knowledge: 58%
- Providing support (emotional, physical and referral): 37%
- Advocating for evidence-based media coverage of HIV: 36%
- Advocating for the rights of all people living with HIV: **34%**

Source: UK Stigma Index (2015) HIV in the UK: Changes and Challenges; Actions and Answers. The People Living with HIV Stigma Survey UK 2015. National Findings. London, United Kingdom

## OUR CONSULTATION: WHAT PEOPLE TOLD US

It is important to engage with partners, people living with and affected by HIV and funders to ensure we continue to add value to Scotland's response to HIV. We've spent considerable time listening in order to develop this Strategic Plan.



118 individuals from across Scotland have responded to HIV Scotland's Online Strategic Plan Consultation and approximately 94 people have attended 5 road shows across Scotland.

## top 3

## People living with HIV said they wanted:

- 1) To see more public awareness building.
- 2 More on challenging stigma and discrimination.
- Training for people who are in direct contact with HIV about U=U and general HIV knowledge.



## People at risk of HIV said they wanted:

- Access to a range of testing opportunities.
- **2** Free self-testing kits.
- **3** More information about HIV transmission and prevention.

## TOP 3

## The Third Sector said they wanted:

- A unified and collaborative response to the challenges of HIV in Scotland.
- 2 Bringing the sector together to develop concrete strategies and campaigns.
- An extended, national campaign to build public awareness of HIV and U=U.



### Health Boards said they wanted:

- More focus on mental health and stigma.
- 2 More on advocating on patient rights and social policy work.
- **1** Improved HIV Testing guidance.

#### WHICH OF THESE WORDS WOULD YOU USE TO DESCRIBE HIV SCOTLAND?

2

3

4

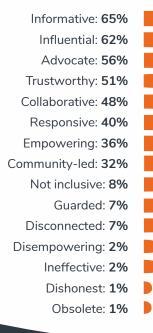
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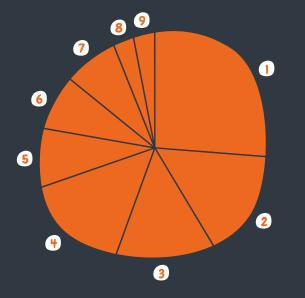
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WHAT DO YOU BELIEVE ARE HIV SCOTLAND'S STRENGTHS? ADVOCATING & LOBBYING INFLUENCE KNOWLEDGEABLE INFLUENCE POLICY PASSIONATE TEAM



### WHICH OF THESE STATEMENTS MOST REPRESENTS YOU?

I am a person living with HIV: 26% I am a person at risk of HIV: 15% I represent a third sector org: 14% I represent a health board: 14% I represent a funding org/co.: 8% I am an academic: 8% I am a civil servant: 8% I am a PrEP user: 3% I am a politician: 3%

### TO WHAT EXTENT DO YOU AGREE WITH THE FOLLOWING STATEMENTS:

	AGREE	NEUTRAL	DISAGRE
HIV Scotland should maintain its strategic focus	77%	20%	4%
HIV Scotland should expand its strategic focus	63%	31%	6%
HIV Scotland should amplify Scotland's success globally	78%	13%	9%
HIV Scotland should provide services	52%	<b>26</b> %	22%
HIV Scotland should expand its scope to sexual health and BBV	53%	18%	<b>29</b> %
HIV Scotland should consider ceasing operations	4%	18%	77%
HIV Scotland should work to support PrEP users	73%	18%	<b>9</b> %
HIV Scotland should provide peer support for people living with HIV	66%	21%	13%
HIV Scotland should provide national testing campaigns and services	82%	11%	7%
HIV Scotland should focus on campaigning to challenge stigma	<b>96</b> %	3%	1%
HIV Scotland should provide local services	51%	27%	22%
HIV Scotland should bring international best practice to Scotland	<b>89</b> %	9%	2%







## OUR VISION

We want Scotland to be a country where everyone has equal opportunities to healthy choices and relationships, and that achieves zero new HIV transmissions by 2030.

## OUR MISSION

Our mission is to forge a positive path to overcome sexual and drug related barriers to healthy lives in Scotland for people living with HIV, PrEP users and people at risk of HIV.

## OUR VALUES

### INVOLVEMENT

We engage people in a meaningful way because we believe the best outcomes are achieved by working together.

### EQUALITY

We foster and promote diversity – everyone has the right to be free from discrimination, to have their choices respected and be valued.

### CREATIVITY

We are a group of creative people and we apply our creativity to problem solving every day in our work to get the best solutions.

### AGILITY

We are action orientated – we proactively find opportunities, assess the evidence and can move quickly on new ideas.

### ACCOUNTABILITY

We use resources wisely; ensure accuracy in our work; make sound decisions and take accountability for our actions.

## OUR PLAN

Our plan focuses our work through 5 distinct themes:

- PREVENTING HIV
- ACCESS TO TREATMENT, CARE & SUPPORT
- MEANINGFUL INVOLVEMENT

## BRINGING THE SECTOR TOGETHERINFORMING THE PUBLIC

### **PREVENTING HIV**

Let's talk about sex and drugs. Did you know that someone living with HIV on effective treatment for more than six months and with an undetectable viral load (that's called Undetectable = Untransmittable) cannot pass on the virus to their sexual partners?

That there's a 'magic' pill (called PrEP) that an HIV negative person can take to prevent HIV? This knowledge and access to these services and medications can prevent new HIV transmissions. We won't shy away from taboo topics like sex and drugs because having frank and open discussions will help us reach **#ZEROHIV**.

So many of our projects that work to inform the public, encourage meaningful involvement, and improve access to testing will also help us prevent HIV. In particular, the new PrEP Advocacy Network will get PrEP users involved in the design and delivery of services that aim to support them.

In addition to the PrEP Advocacy Network, our work over the next three years will:

- Keep people at risk of HIV more informed about HIV prevention methods.
- Ensure everyone has equal and equitable access to HIV testing.
- Reduce the number of people who are diagnosed late.
- Increase access to our HIV Prevention toolkit; including PrEP, injecting equipment provision, testing, condoms, etc.
- Improve sex education and resources in schools by ensuring that the content is created by and for young people.

Every new transmission is preventable. Let's get to work.

## ACCESS TO TREATMENT, CARE & SUPPORT

HIV treatment has given a new lease on life to positive people, who are now learning to age with the virus. HIV is no longer a death sentence, nor does it mean the end of positive people's sex lives either.

Those who are on effective treatment and with an undetectable viral load cannot pass on the virus to their sexual partners. We need to account for the new aging positive population while ensuring everyone has access to treatment, care, and support they need to be undetectable.

The National Patient Survey will allow us to start to think about solutions to key issues faced by people living with HIV. We'll reach the full diversity of people living with HIV across Scotland to highlight people's needs so we can improve their access to treatment, care, and support, enabling them to live healthy, fulfilling lives.

The innovative HIV Ageing Project will build a group of advocates – older people living with HIV – who will help us develop a training conference and webinars to train and support social care providers across Scotland, tackling stigma and developing the workforce across the country.

These projects will ensure that:

• People living with HIV are able to live well into old age.

- People living with HIV can access treatments to ensure viral suppression.
- Everyone has equitable and equal access to quality support services.

In addition to these Year 1 projects, HIV Scotland will:

- Break down the barriers of access to healthcare and support services.
- Address the challenges of stigma and discrimination that dissuade people from getting care and support.
- Lobby the Scottish government to invest in evidence-based treatment and care approaches that people's improve quality of life.
- Ensure service delivery providers provide quality and relevant services that improve people's quality of life.

Everyone has a right to be undetectable. Let's get to work.



### MEANINGFUL INVOLVEMENT

Although society attempts to paint a simple picture of those affected by HIV – gay men, people who use drugs or sex workers – the truth is a diverse array of people are affected by HIV. It's a truly intersectional virus.

This diversity must be a part of any policy, programme, or initiative that aims to support people living with or at risk of HIV. We need to move away from tokenistic involvement and into meaningful partnerships.

Our plan is to harness the full diversity of voices and build a platform for change. Through our Advisory Network of people living with and at risk of HIV, we'll make sure that everyone's voice is heard on the issues that matter. We'll harness the strength in numbers through the Positive Person's Forum to develop a Manifesto for Change, and we'll support people to become advocates in making that change possible. For the first time ever, we'll build a new level of engagement – for PrEP users. We want to make sure that their voice is heard in the design and delivery of services which aim to support them. Our initiatives will ensure that:

- Opportunities exist for PrEP users and people at risk of HIV to be involved in the design and delivery of services.
- Services across Scotland are designed and developed with the input of people living with HIV.
- Decision makers hear the experiences of marginalised groups.

All our projects are developed and implemented in the spirit of solidarity and partnership with the community, and by doing so, we will ensure:

- Our beneficiaries have many opportunities to meaningfully contribute to what we do.
- Our beneficiaries have the right to privacy and confidentiality.

Everyone deserves a voice. Let's get to work.



## BRINGING THE SECTOR TOGETHER

No man is an island, and no organisation can work alone. Working together, the organisations that serve the HIV community can better develop creative solutions to the problems and fill in the gaps in service delivery.

We can ensure that people living with and affected by HIV get the support they need, the platforms to get their voices heard, and access to reliable resources.

In 2020, HIV Scotland will host a brand-new biannual conference, Sex, Drugs & Scotland's Health. This conference will bring together the wider sector and people living with and affected by HIV and hepatitis C to highlight emerging policy issues, share research, and celebrate our successes. The conference will put people at risk, living with, or affected by HIV in the room with clinicians, politicians, other third sector organisations, and researchers.

This conference will create opportunities for:

- Building a unified approach to tackling HIV in Scotland.
- Influencing policy makers.
- Sharing best practices and celebrating achievements between the third sector, health services, academia, and beyond.

Alongside this exciting new conference, we'll be working to:

- Promote an inclusive environment where ideas thrive.
- Bolster great working relationships within and outwith the HIV sector, bringing together the third sector, clinicians, researchers, and others.
- Connect people living with and affected by HIV with parliamentarians through the Scottish Parliament's Cross Party Group on Sexual Health & Blood Borne Viruses
- Identify gaps in services, care, and support, and bring service delivery partners together to ensure no one is left behind.
- Encourage critical discussions about the challenges of HIV.
- Look abroad for international best practices.
- Share our successes with the international community.

An effective organisation is a collaborative one. Let's get to work.



### INFORMING THE PUBLIC

HIV is shrouded in myth and mystery. Many people in Scotland still believe that HIV can be transmitted via kissing, that HIV is a death sentence, that only the 'wrong' kind of people get HIV.

These misconceptions lead to HIV stigma. Stigma robs people of their voices, harms their mental health, and breeds fear that stops people from getting tested or treatment.

As a partner in the Fast-Track Cities initiative, we will work with local city leaders to develop plans for Scotland's cities to achieve zero HIV-related deaths and eliminate HIV stigma. Our ambition is to fast-track Scotland to reach **#ZEROHIV** by ensuring all seven cities are signed up for the Fast-Track Cities initiative. We will also use the power and accessibility of creative activism to engage the public. Building on the work of our book Disclosures, we will create an online space for people affected by HIV to share their stories.

In Year 1, our Fast-Track Cities project and a focus on creative activism will:

- Give young people better access to inclusive education about HIV and reduce HIV stigma.
- Shape public attitudes and knowledge about HIV so that more people are aware of the realities of how to contract, be tested for, and live with HIV.
- Ensure policies and practices in Scotland do not discriminate against people living with HIV.
- Celebrate success and share learning with global partners.

Alongside these activities, HIV Scotland will be working to bust myths and fight stigma by:

- Informing young people and students about sexual health, stigma, and HIV prevention and transmission.
- Promoting reliable and relevant information on HIV testing and ageing with HIV.
- Connecting with healthcare staff to ensure they are well-informed about HIV and stigmatising behaviours.
- Working with the government to promote nonstigmatising legislation.
- Engaging with the media to ensure they report on HIV accurately and without encouraging stigma.
- Looking for creative ways to be sure the public is well-informed about HIV.

#### Myths are made to be busted. Let's get to work.



### **MEASURING IMPACT**

HIV Scotland has bold ambitions to prevent HIV, improve access to treatment, care and support, encourage meaningful involvement, bring the sector together, and inform the public.

Our projects in Year 1 and beyond will undoubtably make an impact on people living with HIV and those at risk of HIV while influencing the HIV community and keeping the general public informed. But how do you measure this kind of impact?

For each project, HIV Scotland evaluates the project's effectiveness by gauging against our desired outcomes – to continually improve the lives of people living with and at risk of HIV. These project benchmarks help us look forward and ensure all our work contributes to our goals of **#ZEROHIV**.

The data we collect will ensure there are measurable local and national policy recommendations in line with our overall objectives. We will promote this data as an evidence base to the National Monitoring and Research Group, which evaluates the progress of Scotland's national HIV strategies. We want (and need) to involve the community we aim to strengthen. Not only do we gather data, but we work directly with the people we serve to learn what they want and need changed to get the best care and support.

Measuring our impact as a policy organisation has always been difficult. As we evolve from an organisation that researchers and identifies problems to one that provides solutions, we will maintain our commitment to both quantitative and qualitative forms of measurement.



## our outcome chain

PRIMARY OUTCOME: PREVENTING HIV ACCESS TO TREATMENT, CARE & SUPPORT

### SHORT TERM OUTCOMES (1-3 YEARS)



MEANINGFUL INVOLVEMENT
EDUCATING THE PUBLIC
BRINGING EVERYONE TOGETHER

### MEDIUM TERM OUTCOMES (3-6 YEARS) LONG

### LONG-TERM GOALS (2030)

A significant reduction in new transmissions and late diagnoses.

> Everyone affected by HIV has opportunities to co-design and develop services, and have their experiences heard by decision makers.

The national response to HIV is based on a collaborative partnership approach, underpinned by international best practice and evidence. People living with HIV can access the treatment, care and support that they need to live well.

Society is well-informed about the 21st Century realities of HIV. ZERO NEW HIV INFECTIONS

> ZERO HIV-RELATED DEATHS

ZERO HIV-RELATED STIGMA OR DISCRIMINATION

## YEAR ONE ACTIVITIES

### NATIONAL PATIENT SURVEY

The National Patient Survey will highlight the experiences of the full diversity of people living with HIV across Scotland, to identify their needs and improve access to treatment, care and support to ensure they can live healthy, fulfilling lives.

### **FAST-TRACK CITIES**

Our ambition is to Fast-Track Scotland, to ensure all seven cities are signed up to the global Fast-Track Cities initiative. We'll work with local city leaders to develop plans to ensure that each of Scotland's cities is working towards achieving zero HIV-related deaths and zero HIV-related stigma.

#### **HIV AGEING PROJECT**

This innovative project will build a group of advocates who will be older people living with HIV, to develop a training event and webinars to support and social care providers across Scotland, tackling stigma and educating the workforce across Scotland.

#### **CREATIVE ACTIVISM**

Building on the work of our book, Disclosures, we will develop an online space for people affected by HIV to take part in creative activism by sharing their stories – fiction & non-fiction.

#### **CROSS PARTY GROUP**

The Scottish Parliament's Cross-Party Group on Sexual Health & Blood Borne Viruses brings together the wider sector and people living with and affected by HIV and hepatitis C and connect them with parliamentarians to highlight key and emerging policy issues.

#### ADVISORY NETWORK

HIV Scotland's Advisory Network brings together patient advocates from across Scotland, representing the full diversity of people living with HIV, to ensure that HIV Scotland's policy work is grounded in the lived experiences of people living with and affected by HIV.

#### **POSITIVE PERSON'S FORUM**

The Positive Person's Forum will bring together people living with HIV to develop a Manifesto for Change which will highlight the top priorities of people living with HIV, and what they need to be able to live long, healthy and fulfilling lives. HIV Scotland will support local advocates to campaign for change using this manifesto.

#### PUBLIC AWARENESS CAMPAIGNING

To tackle HIV-related stigma, HIV Scotland will embark on an extensive public awareness campaign to bust myths surrounding HIV and inform and educate the general public, including work with schools to educate young people.

## FUNDRAISING

#### PrEP ADVOCACY NETWORK

The concept of greater meaningful involvement for people living with HIV is one that is understood, however no system for the involvement of PrEP users is currently established in Scotland. We will establish a PrEP Advocacy Network to allow PrEP users to be involved in the design and delivery of services which aim to support them.

#### **PRIMARY CARE CHAMPIONS**

This is an innovative project designed to build the capacity and skills of primary care nurses and GPs to undertake effective and efficient HIV testing which is free from stigma and discrimination, with the ultimate aim of reducing late diagnosis and minimising the proportion of individuals with undiagnosed HIV.

### SEX, DRUGS & SCOTLAND'S HEALTH CONFERENCE

This brand new, bi-annual conference will take place in 2020. Organised by a crosssector partnership, this conference will be used to highlight new and emerging issues and research, support workforce development and connect the sector and those working with in the SHBBV field in Scotland, the UK and internationally. For a quarter of a century, the vast majority of funding to run HIV Scotland, around £300,000 a year, came almost exclusively from the Scottish Government. In 2018, this changed and we were in serious danger of closing forever.

We never want to be in that situation again and leave people living with HIV in Scotland without a champion to fight for their rights and ensure that they have stigma-free access to the best possible care to live long and healthy lives. Therefore, we will seek funding from a vast variety of sources to ensure we are selfsufficient come 2021 when the Government funding ends completely.

Since 1996, we have achieved so much. In 2018, Scotland became the first UK nation to provide PrEP on the NHS; a drug proven to reduce HIV transmission by 86%. This was thanks largely to pressure from HIV Scotland, who used sound evidence and consultations with the people affected by and at risk of HIV to influence lawmakers. We are now striving to ensure that there are no new HIV infections or HIV-related deaths in Scotland by 2030 through our groundbreaking **#ZEROHIV** campaign.

Our work doesn't just help people get by; it helps them thrive.

contd.

Together we can build a brighter future for people affected by HIV and where fear of infection is a thing of the past. Our new ambitious fundraising strategy will allow us to do just that.

As before, our supporters, partners, and volunteers are essential to make this happen. Our initial focus will be on increasing funds from grant-making organisations, statutory sources and corporate partners. However, every single person can help in so many ways. Our volunteers will continue to donate their precious time to help to change attitudes and improve access to lifeenhancing services.

To raise £160,000 in 2019 rising to £300,000 per year by 2021 won't be easy for our small team but it is essential to continue to do what we do. With your support, the sky's the limit.

Join us and be a part of that positive change.

## **2019-20** Scot Gov: **£100,500** Total target: **£160,000 2020-21** Scot Gov: **£80,400** Total target: **£210,000 2021-22** Scot Gov: £0 Total target: £300,000





## HIV.scot **f** HIVScotland

### THE HIV CHARITY FOR SCOTLAND

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