



## What you need to know and how you can take action

Thank you for standing with people living with and affected by HIV by signing up to the General Election 2017 HIV manifesto. We want to put HIV on the agenda this election.

Now help us spread the word!

Start talking to all your local candidates about the seven pledges in the HIV manifesto and how they can pledge their support. You can do this by:

- Writing to all your local candidates, using [our e-action tool](#).
- Approaching all your local candidates on social media, asking them to pledge their support for the HIV manifesto and tweet their support.
- Attending local 'hustings' events and asking questions (we have written some below to get you started).
- Asking for a meeting with local candidates.
- Speaking to any local candidates who knock on your door and ask them to sign up to the HIV manifesto.
- Tell us what your local candidates have said! Email: [HIVactivist.org.uk@nat.org.uk](mailto:HIVactivist.org.uk@nat.org.uk)

This document has further information on each of the seven pledges, with key facts and stats you may want to know and questions you can ask all your local candidates.

As some aspects of Government are devolved, not all decisions which Westminster MPs will make will change the policy in each of the four nations. For example, Westminster makes decisions about health and social care for England, but Scotland, Wales and Northern Ireland make their own policies in these areas. However, MPs from every nation of the UK have a vote in Westminster and they also have an important voice in decision-making in their home nation – so it is worth talking to all your local candidates, wherever you are.

## Top tips when engaging with local candidates

- Make it clear that you are a local constituent – candidates will be interested in hearing local issues from potential future constituents (also ensure your address is on all emails and letters!)
- As well as asking local candidates to sign up to the manifesto, think beforehand on which key questions from the below you want to ask the candidate. Be clear on what you want to raise, and what response you want – you will only have a short amount of time with them so make it count!
- Utilise events your local candidates are attending - hustings, speeches, local fairs and community events (or even if they're just out canvassing). They will be out and about in the community a lot during the campaign.
- Don't be afraid to approach the candidates, whether at hustings or an event. Candidates are there to listen to the local community – which includes you!
- Use social media as much as you can. Social media is an integral part of modern campaigning and candidates are highly likely to be using social media in the run up to election. It is an incredibly effective way to engage with your local candidates as well as publicise their response. Take a look at the HIV [manifesto webpage](#) for some model tweets to get you started.
- **DON'T FORGET:** You can find our printable #HIVManifesto pledge board on the [HIV Manifesto webpage](#) – don't forget to print out and get a photo of your local candidates with the pledge board.
- Know the facts! Read the relevant sections in this document. Going in prepared with up-to-date knowledge will mean you can adjust the questions to match the context in which you are meeting your candidate in, as well as making it easier to push for a proper answer.
- Do share with us how your local candidate responded – it will help us in engaging parliamentary champions after election time. Email [HIVactivist.org.uk@nat.org.uk](mailto:HIVactivist.org.uk@nat.org.uk)

### Try to avoid:

- Assuming your local candidates will know all the facts, we need to educate as well as engage.
- Being confrontational.
- Don't forget to follow up, we need to hold MPs to their pledges after they are elected.

## 1. Commit to tackling the stigma and discrimination faced by people living with HIV

### Questions to ask about HIV stigma and discrimination

1. What will you do to address HIV stigma in the NHS so that people living with HIV can access healthcare without fear of discrimination?
2. Will you challenge HIV stigma and discrimination when you come across it locally, in parliament and beyond?
3. How will you work with the NHS and community partners to reduce the stigma around HIV testing?
4. What will you do to ensure people living with HIV who experience discrimination in the workplace or elsewhere have access to justice?

## Key Information

Stigma and discrimination have a harmful effect on people living with HIV and the HIV epidemic. Stigma is linked to poorer adherence to HIV treatment and treatment outcomes and dramatically hinders HIV prevention. Studies also link stigma to increased risk-taking, non-disclosure, avoidance of health services, fear and avoidance of HIV testing.

One in five people living with HIV have experienced verbal harassment or threats. A third have had their HIV status disclosed without consent by a friend or family member. (Source: *The HIV Stigma Index UK, 2015*)

Stigma affects people living with HIV in those settings where they should feel the most supported – including NHS and social care services. 40% of respondents to the HIV Stigma Index had experienced at least one instance of being treated differently in a healthcare setting due to their status.

The impact of this stigma is significant. 18% of respondents to the HIV Stigma Index reported having had suicidal thoughts within the past 12 months. Around half reported feelings of shame, guilt, low self-esteem, and self-blame in relation to their HIV status.

There is still a significant number of people who report negative attitudes towards people living with or affected by HIV. In 2014, 23% of people agreed with the statement 'I don't have much sympathy for people with HIV if they were infected through unprotected sex' (Source: *Ipsos Mori poll for NAT, 2014*).

Legislation in the UK classifies HIV as a disability. This should protect people living with HIV from discrimination. But, this relies on awareness of the law amongst potential perpetrators and victims of discrimination. It also relies on adequate access to justice. People's ability to challenge discrimination is becoming more difficult with reductions in funding for the advice sector, legal aid and specialised HIV services across the UK.

## 2. Fully fund HIV and sexual health services to meet the needs of local communities

### Questions to ask about HIV and sexual health services

1. How will you work with local health and social care bodies to ensure that local HIV and sexual health services are able to meet the needs of your constituents?
2. Will you call for fully-funded HIV and sexual health services for your area and challenge cuts to services when they occur?
3. If you are elected, will you visit a local HIV service to find out about the vital work they do for people affected by HIV, and support them to maintain their funding?

## Key Information

HIV is preventable and we have the tools we need to end transmission. It is also a long-term condition, which over 100,000 people in the UK will have for the rest of their lives. An effective HIV response therefore requires an entire pathway of services, spanning prevention, testing, sexual health services, treatment, social care and other non-clinical support. Yet cuts to budgets and confusion about responsibility means there are serious gaps in services in many local areas.

Health and social care are devolved matters, so Westminster MPs will be making decisions which affect England only. However, as local constituents in Wales, Scotland and Northern Ireland it is important that MPs in those countries know when there are access or other issues around local HIV and sexual health services.

It is vital that fully funded services are in place that can meet the HIV and sexual health needs of local populations yet in many places across the UK services are threatened, and some have already faced severe cuts.

Access to sexual health services across Wales continues to deteriorate, with vital services being entirely de-commissioned across the nation. This has left some people having to travel 60 miles to access their nearest sexual health clinic and has coincided with an increase in STI transmission in Wales.

The 2013 restructure of the health system in England fragmented responsibility for HIV services across multiple bodies. Responsibility is now split across NHS England, local authorities and clinical commissioning groups – with no-one responsible for the overall picture.

While the quality of HIV clinical services has so far been maintained, other vital services are struggling including HIV support services. These include peer support, professional advice and advocacy on a range of matters important to people living with HIV (including sex and relationships, condition self-management, and psychosocial issues). One in three people living with HIV access support services every year to help them manage their HIV.

Local authorities in England have historically taken on funding for HIV support services and some have continued to do so as part of their public health and social care responsibilities. But rapid cuts to local authority budgets means that HIV support services are being drastically cut.

### **3. Recognise the importance of prevention to a sustainable health and social care system by increasing investment in public health services**

#### **Questions to ask on public health and HIV prevention**

1. Will you take action and call for an increase in investment in public health services?
2. What will you do to ensure that sufficient resources are being provided for HIV prevention services?
3. How will you address the needs of communities affected by health inequalities?

## Key Information

Funding for public health is determined by each of the four nations separately. In 2013/14 £570 million was spent on HIV treatment in England. The UK spends a fraction of this on prevention, despite political acknowledgement of the importance of preventing ill-health – both for the individual at risk and in order to save the NHS money in treatment costs.

Recent reports that a drop in new HIV diagnoses has been recorded by some London sexual health clinics show that it is possible to reduce the growth of the epidemic – but we need to use the tools we have available. This decline has not been seen in other parts of the UK. There are also wider sexual health prevention issues; over the past decade diagnoses of gonorrhoea, syphilis, genital warts and genital herpes have increased considerably, especially among men.

In England, there have been drastic cuts to the funding available for prevention. The national budget allocation for public health services – which pays for sexual health clinics, HIV prevention and drug and alcohol services - was cut by £200 million in 2015-16, with further 3.9% cuts every year for future years. From April 2019, the public health budget in England will no longer be ring-fenced leaving these services, including HIV prevention, even more vulnerable to local cuts. Local authority spending for HIV prevention dropped by a third from 2015 to 2017, despite rates of HIV being unchanged during this time.

Poor health is not evenly distributed across society. Public health cuts have a disproportionate impact on health, including sexual and reproductive health, in areas of high deprivation, and on already disadvantaged groups such as men who have sex with men, women, young people, and BME communities.

## **4. Equip schools with the resources they need to ensure that high-quality, age-appropriate, LGBT-inclusive sex and relationships education is taught to all young people in all schools**

### **Questions to ask about sex education in Scotland, Wales and Northern Ireland**

1. Will you contact the Government and call for statutory sex and relationships education for all young people in all schools across the country?

### **Questions to ask about RSE in England**

1. Will you take action to ensure that RSE is fully-funded in all schools, that teachers are trained properly, and that there is mandatory, good quality continual professional development for all that teach it?
2. How will you ensure that issues such as sexual health and LGBT-inclusive RSE are not simply tick-box exercises but are at the heart of all core RSE lessons?
3. Will you act to ensure that in any consultation on RSE, young people are properly engaged with - before, during and after the consultation so that they can have their voices heard at each stage of the process?

## Key Information

Sex and relationships education prepares children and young people for the physical, social and emotional changes they are going to face.

Sex and relationships education is not yet mandatory in all schools in Wales, Scotland and Northern Ireland. In England the Government has recently committed to ensuring that RSE (relationships and sex education, previously SRE) is delivered by September 2019 in all schools in England. Now we need to ensure that the guidance on RSE emphasises sexual health and is gender and LGBT-inclusive. Young people must be involved in designing RSE if it is to fully meet their needs.

We know that sex and relationships education improves the sexual health of young people, yet it is inadequate or absent in many schools across the UK. 97% of young people surveyed for a recent report thought sex and relationships education should be LGBT inclusive, but 95% were not taught about LGBT relationships (*Source: Terrence Higgins Trust 'SRE: Shh... No talking'*). A third of young gay and bisexual men – the young people at highest risk of HIV acquisition - did not receive any information on HIV and safer sex in sex and relationships education (*Source: NAT, 'Boys who like Boys'*). Education must consider the needs of all genders and include a focus on issues around consent, violence and coercion.

For sex and relationships education to be effective, it has to be taught to a high standard by teachers who have access to good training and high quality support from specialist organisations. Training and support must be a part of Initial Teacher Training and Continuing Professional Development.

In England, the Government has committed to updating its guidance on RSE, which is 17 years out of date. Guidance must ensure that RSE is LGBT inclusive and gives appropriate emphasis to sexual health. The Government must listen to the full range of perspectives from young people, to ensure that re-designed RSE is effective for all.

## 5. Make PrEP available to all individuals at risk of HIV in the UK

### Questions to ask about PrEP

1. Will you commit to ensuring that PrEP is made available on the NHS to all who are at risk of HIV?
2. Will you commit to ensuring that all those at risk of HIV have access to the PrEP trial regardless of where they live? (*Applicable in England*)

## Key Information

Pre-exposure prophylaxis (PrEP) is a highly effective way of preventing people from acquiring HIV and involves people who are HIV negative taking anti-HIV drugs when they are at risk of exposure to HIV.

Scotland is leading the way and has recently announced that PrEP will be made available via the NHS. In Wales the Government has just announced a pilot that will ensure that all who are at risk of HIV will be able to access PrEP. England and Northern Ireland are lagging behind - PrEP is only available to people enrolled in a PrEP trial in England and is not available on the NHS in Northern Ireland.

The World Health Organisation (WHO) has recommended that PrEP should be made available immediately for all individuals at substantive risk of HIV.

Two European studies of PrEP reported early results in October 2014. Both studies showed that PrEP was so effective at preventing HIV transmission that everyone in these studies were immediately offered PrEP on an ongoing basis.

In light of this news, together with data on continued high rates of new HIV infections, Governments urgently need to find a way to make PrEP available across the UK.

In England, an ongoing battle has been raging after [NHS England suddenly abandoned its own process](#) for the approval of PrEP, stating that 'NHS England is not responsible for commissioning prevention services'. After much wrangling, including NHS England being taken to court by the National AIDS Trust, in December 2016 [NHS England announced](#) that they will fund a PrEP trial for 10,000 people as the first step in a national roll-out of PrEP. This was welcome news but there are many questions to be answered about the trial.

PrEP is a highly effective and cost-effective weapon against HIV - we can't afford not to provide PrEP on the NHS in every nation of the UK. All who are at risk of HIV should have access to PrEP, regardless of where they live.

## **6. Develop a fair benefits system that meets the needs of people living with HIV whether in or out of work**

### **Questions to ask about benefits**

1. Will you take a stand against further cuts to disability benefits in the next Parliament?
2. How will you act to ensure that people living with HIV are treated fairly by the benefits system and that their barriers to work and participation are recognised?
3. What will you do to represent the needs of people living with HIV who are living in poverty due to cuts to disability benefits?

### **Key Information**

For nearly a decade people living with HIV who need to access disability benefits have been subject to cuts and demanding new assessment processes. This has had a negative impact on the physical and mental wellbeing of people living with HIV who face the greatest barriers to participation.

There are two main forms of welfare benefit which may help people living with HIV who find their physical and/or mental health presents barriers to full participation:

- Income replacement benefits: **Employment and Support Allowance (ESA)** is the main benefit for people who can't currently work due to their long-term condition or disability.
- Extra costs benefits: **Personal Independence Payment (PIP)** is gradually replacing **Disability Living Allowance (DLA)** as the main benefit to help people with the extra costs of living with a long-term condition or disability.

Disability benefits assessments are demanding and have been a cause of significant distress to people living with HIV, as well as putting extra pressure on already stretched healthcare and voluntary sector professionals who support them. They take a 'functional', tick-box approach, which does not accurately capture the complexities of HIV. As a result, people living with HIV are missing out on the support they need.

The recent cuts made to the rate of ESA for new claimants in the work-related activity group means that even those who pass the assessment will have to make do on £30 less per week.

People living with HIV are disproportionately affected by poverty. 15% of people accessing HIV care said they were falling behind with bills, compared to 6% of the general population. A third (33%) of people living with HIV say they sometimes skipped meals because of poverty – a further 17% did so often (*Source: Positive Voices Survey, Public Health England*). UK clinical studies have found that those experiencing financial hardship are less likely to fully benefit from HIV treatment – this means that poverty is undermining the work of the NHS.

## 7. Ensure that the health and social care system is equipped to meet the needs of a population ageing with HIV

### Questions to ask about HIV and Ageing

1. Will you take a stand and commit to ending stigma and discrimination towards people living with HIV in social care?
2. If elected, will you commit to supporting HIV organisations, ageing organisations, and local health and care providers to ensure the health and social care sector is ready to support people growing older with HIV?

### Key Information

With the success of modern treatment and an ageing population, we are seeing the first generation of people with HIV living into older age. This is a cause for celebration, but the health and social care



system is not yet ready to meet the needs of this population, or the challenges they currently face - from discrimination in social care, to management of multiple co-morbidities.

A third of all people with HIV in the UK are aged over 50- and this is expected to rise to over 50% by 2028 (*Source: Public Health England*).

Of those aged over 50 who are accessing HIV care in the UK, three-quarters have at least one other long-term health condition, in addition to HIV (*Source: Public Health England, Positive Voices Survey*).

A UK survey of people living with HIV who are aged 50 and over found that 22% rated their current wellbeing as 'bad' or 'very bad' and 82% reported significant loneliness (*Source: Terrence Higgins Trust, Uncharted Territory*).

Over 50s living with HIV increasingly need to access social care, but this is a cause of concern for many. Some have been subject to discrimination and breaches of confidentiality from social care professionals due to their HIV status, and others who have not yet accessed care fear this will happen to them. Older people living with HIV are already disproportionately affected by poverty and 88% do not have any financial plans to fund future care needs *Source: Terrence Higgins Trust, Uncharted Territory*).

Thirty years ago, people living with HIV did not expect to reach this stage in their life – and nor did health and care services. The next Government needs to ensure we are ready to meet their needs.