

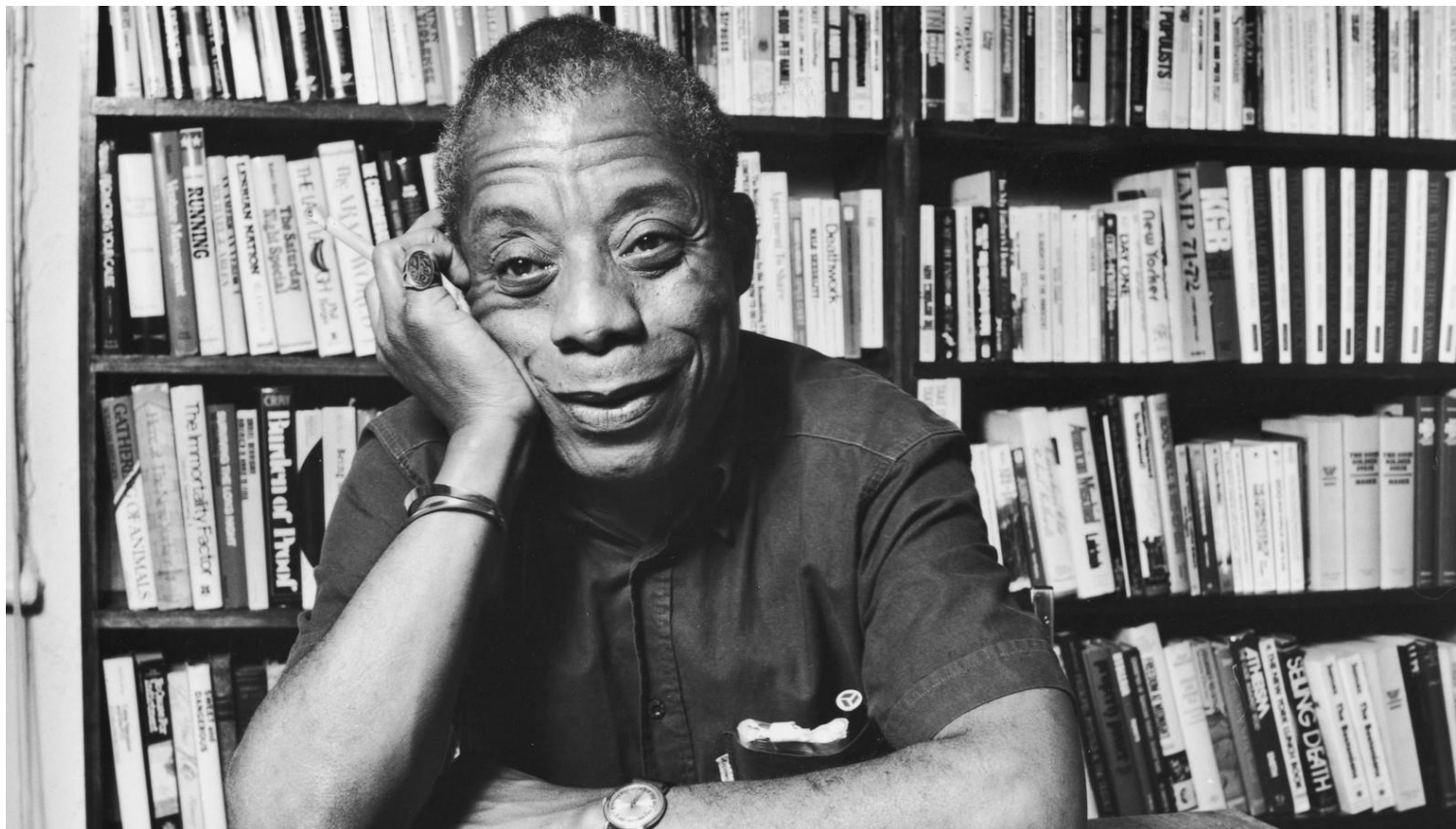
# Challenging Discrimination

Daniel Fluskey, Director of Policy, Research,  
and Influencing



**NATIONAL  
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Securing rights  
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# Stigma vs discrimination

While stigma refers to an **attitude or belief**, discrimination is the behaviors that result from those attitudes or beliefs. HIV discrimination is the act of **treating** people living with HIV differently than those without HIV. <https://www.cdc.gov/>

Discrimination = institutional and actualised stigma

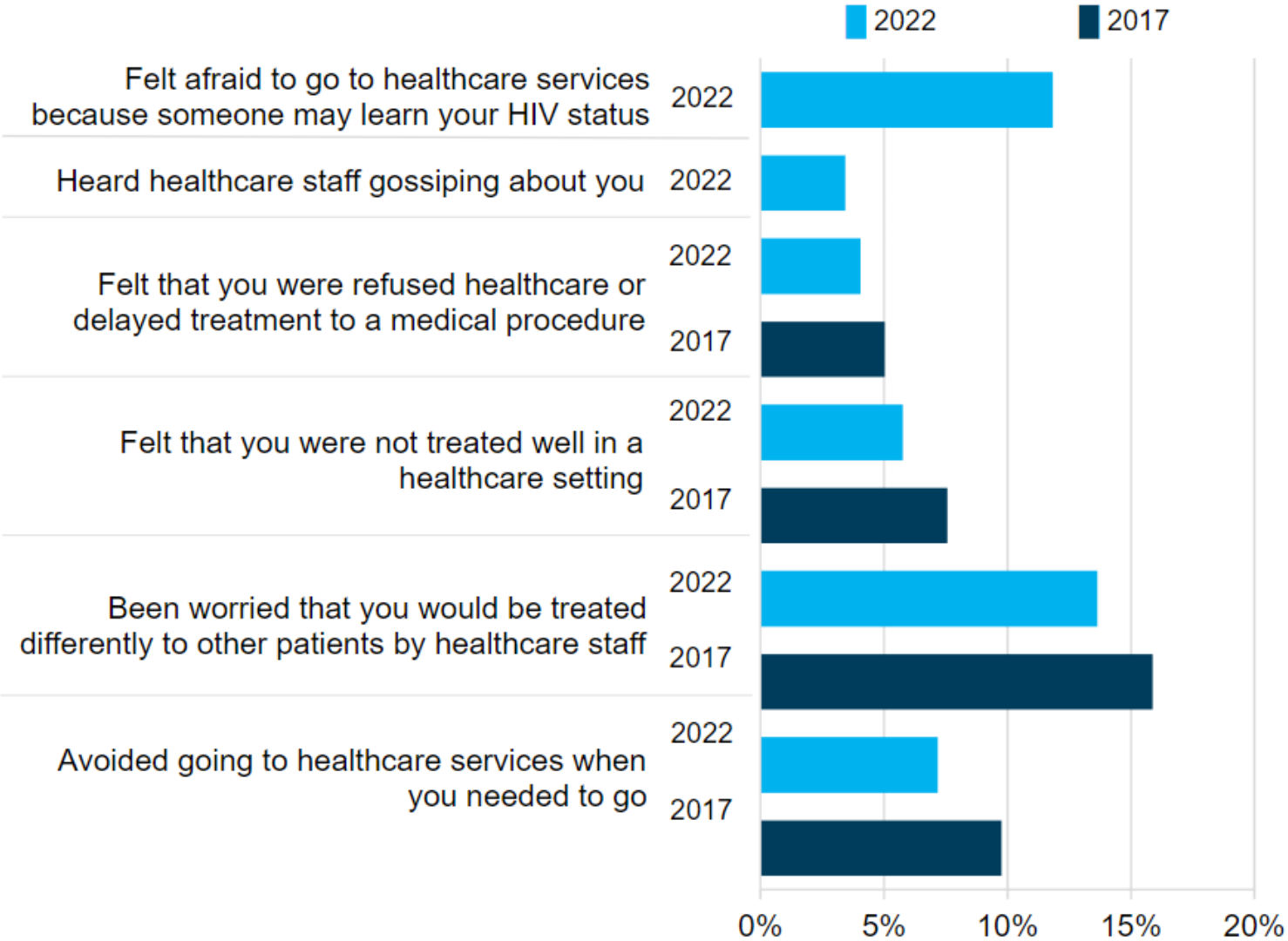


# Why challenging discrimination matters

- No one should be treated poorly, denied a service, or receive a worse experience than others because of their HIV status
- Often unlawful, but institutions/orgs often only change when called out
- Discriminatory policies perpetuates stigma – vicious circle
- Empowering



**Figure 21. Percentage of people living with HIV reporting stigma in healthcare settings in the last year, 2017 and 2022**



# The Equality Act 2010

HIV is classed as a disability under the Equality Act **from the point of diagnosis**

- Age
- **Disability**
- Gender reassignment
- Marriage and civil partnership
- Pregnancy and maternity
- Sex
- Sexual orientation
- Race
- Religion or belief

# The Equality Act 2010

The Act prohibits, amongst other things:

- Direct discrimination
- Indirect discrimination
- Discrimination arising from disability
- Discrimination by perception
- Harassment
- Victimisation

**There is often  
overlap between  
different types of  
discrimination**

# Examples

- Direct discrimination:
  - if a person living with HIV is denied a tattoo purely because they are living with HIV, this is direct discrimination.
  - putting PLWHIV at the end of a cosmetic surgery list



# Examples

- Indirect discrimination:

For example, if a cosmetic surgery clinic has a policy that a customer must disclose their full medical history with the clinic in order to obtain treatment, this would be 'indirect discrimination'

# Examples

- Discrimination arising from a disability

For example, if a tattoo parlour required an individual living with HIV to disclose their viral load status prior to getting a tattoo, this would be considered 'discrimination arising from a disability'.

# Examples

- Discrimination by perception

For example, if a tattoo parlour refused a tattoo to someone because they presume they are living with HIV

# National AIDS Trust's Discrimination Advice service



## Discrimination Service for Individuals

National AIDS Trust provides advice and support to people living with or affected by HIV who have faced discrimination. This service is free of charge.

### We can:

- Talk through a situation which you think may be discrimination
- Provide you with advice, including legal advice through our partner solicitors specialising in discrimination law and employment law
- Represent you and advocate on your behalf for example by drafting letters of complaint
- Support you to use regulatory complaints procedures for private and public bodies
- Advise on taking legal action\*
- Maintain your anonymity where requested and always uphold confidentiality

\*Please note that we cannot guarantee legal representation, nor can we fund legal fees outside of the advice we provide from our solicitors.

The information provided through this service is informed by advice from our legal partners at Deighton Pierce Glynn and Leigh Day.



# Successful challenges

- Between 1st July 2023 and 31st December 2023, there have been **28** changes to organisational/institutional practices
- A pharmacy that would only vaccinate with full PPE = policy change and training

# Successful challenges

- Challenging an employer's discriminatory absence management policy (the issue was escalated due to them being off sick managing HIV and cancer)
- We supported them to help **advocate for themselves**. The process de-escalated, and organisation agreed with the evidence that it was discriminatory on the grounds of the individual's HIV status.

# Successful challenges

- Individual couldn't get appointments/treatment at their local sexual health clinic due to previous complaint about data being held
- Potential victimisation under Equality Act – secured access and influenced their policy

# Influencing change



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## Hospital staff failed man living with HIV by unnecessarily delaying surgery

1 December 2023

A hospital that unnecessarily delayed a man's surgery at the last minute because he had HIV failed in their care, according to England's Health Ombudsman.



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# Influencing change

- After a campaign lasting over 4 years, we finally convinced the Government that it was necessary to change discriminatory laws that prevent many people living with HIV from accessing fertility treatment – to allow all people living with HIV with an undetectable viral load to donate sperm or eggs.

# Influencing change

- Numbers and trends of cases relating to data protection and sharing of data without consent
- Engaged ICO to raise concerns
- New project to review guidance and complaints process

# From challenge to change

- Discrimination is often by mistake/oversight (people don't realise they're breaking the law!)
- Use the science (minds, rather than hearts)
- Share the impact, make it human
- Advocating WITH someone living with HIV (not for)
- Use a challenge as a lever to bring about change



# From challenge to change

*“Can I just say thank you, I mean that from the bottom of my heart. Your support, kindness and dedication has been appreciated, well beyond words. I couldn’t have got to this point without you - genuine. I don’t think I would’ve been able to even deal with what happened without you.”*

*“This is approach exactly what I needed - I can’t tell you how much this means to me!*

*“Your assistance has been invaluable, and I truly appreciate all the help you've given me. Your support has been instrumental in making progress.”*

<https://www.nat.org.uk/hiv-rights/discrimination-advice>



# Making the Change

## The Clinicians Role



Dr Joseph Heskin

Consultant in GenitoUrinary and HIV Medicine

10HB Clinic

Chelsea and Westminster NHS Foundation Trust

# Gather like minds

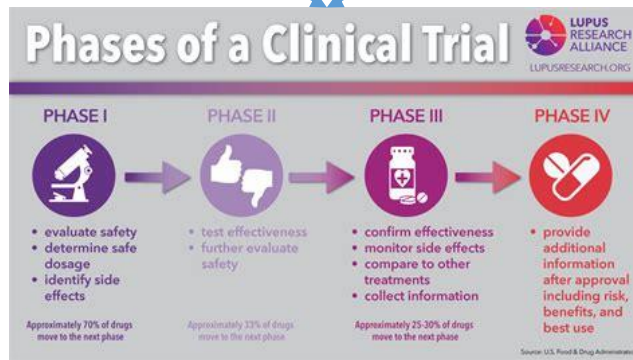
**You cannot tackle stigma if you don't include the community experiencing it**

- **Clinicians**

- Clinical expertise
- Extensive community interaction
- National reach
- Be curious
- Ask the community
- Question existing rules/regulations
- Raise concerns to a national level



# Evidence



# Evidence – when it's lacking

- Military/Aviation/Sport
  - No trials
  - Existing literature outdated
- What do you do?
  - Search, Search, Search
  - Extrapolate
  - Prepare



# Challenges

- The burden of history
- Ignorance – learned, absorbed, manipulated, unintentional
- The roots of discrimination
- Identifying drivers to change
- Changing attitudes in healthcare
- Pace of institutional change





**Military**

● This article is more than 1 year old

## UK armed forces end HIV being a barrier to overseas deployment

Serving personnel taking suppressive treatment will be recognised as fully fit for all service from Tuesday

UK pilots with HIV able to work unrestricted after 'landmark changes' in aviation guidance

Previously, those who disclosed they had HIV were automatically required to undergo cognitive testing to assess their mental abilities - a complex and expensive process.

Press release

### Landmark change to blood donation criteria

Men who have sex with men in a long-term relationship will be able to donate blood in England following changes to blood donation criteria.

From: [Department of Health and Social Care](#)  
Published 14 December 2020

Press release

### IVF law change to benefit couples with fertility issues

End of outdated law which requires same-sex couples to pay up to £1,000 for safety screening when accessing fertility treatment.



NEWS | HEALTH

## Couples with HIV to gain access to fertility treatment under new laws

Changes announced by the Government also mean same-sex couples will no longer have to pay for expensive screening if they want to undergo IVF.



Press release

### Final barriers removed for Armed Forces personnel with HIV

People with HIV, but no detectable virus, are now able to join the military and fully deploy on operations

From: [Ministry of Defence](#)  
Published 21 June 2022

Landmark change to blood donation eligibility rules on today's World Blood Donor Day

14 June 2021



# Influencing for Change

**Debbie Laycock**

Head of Policy and Public Affairs

Terrence Higgins Trust

# Nothing About Us, Without Us

- Greater impact working hand in hand with affected individuals/communities
- BUT need to be led by individuals on what they are comfortable with
- Need to ensure individuals are fully supported





# Routes to influence

- Direct contact
  - Setting out the case
- Behind the scenes influencing
  - Working with allies
  - Who has power and influence internally?
- Parliamentary pressure
  - Make some noise!
  - Smart lobbying
- Media pressure
  - Telling a story

## Lifting rules for HIV-positive pilots 'phenomenal'

🕒 24 June 2022



# How to influence

- Identifying who has the power to directly make change
  - Individual organisation, local council level, national level policy, or legislative change needed?
- Identifying who has the influence to indirectly make change
  - Local MPs, councillors and mayors
  - APPG on HIV
  - National health orgs – BASHH/BHIVA
  - NAT and THT
- Galvanising supporters – NAT Fertility Rights Campaign

# Change can take time...

- It can take a while...
- You are likely to face barriers and “blockers”...
- Your patience will wear thin...
- But you will get there!

Thank you!



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News story

## Armed Forces make major changes to end HIV being a barrier to service

A number of changes that will make it easier for people with HIV to pursue a career in the Armed Forces have been announced on World AIDS Day.