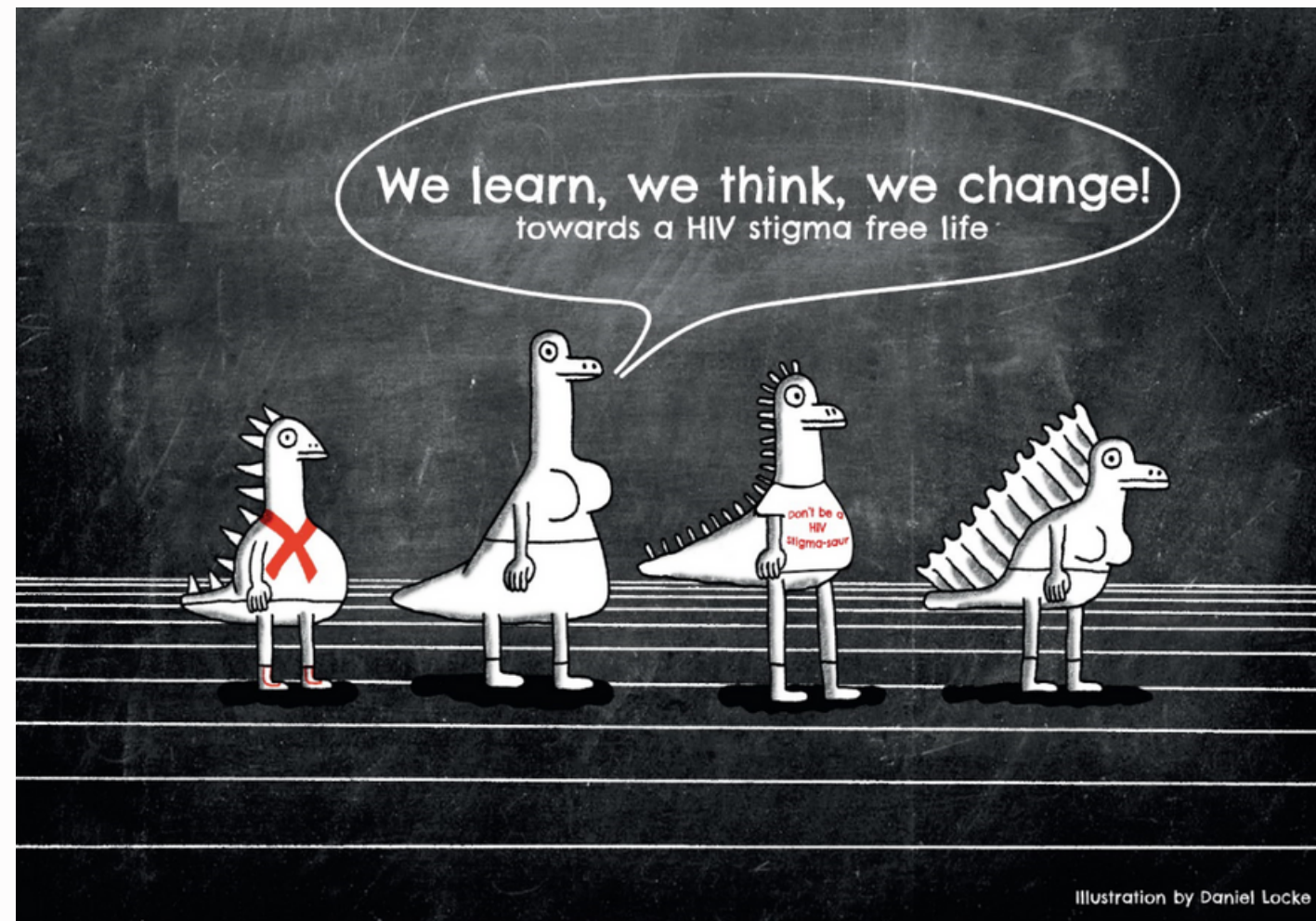


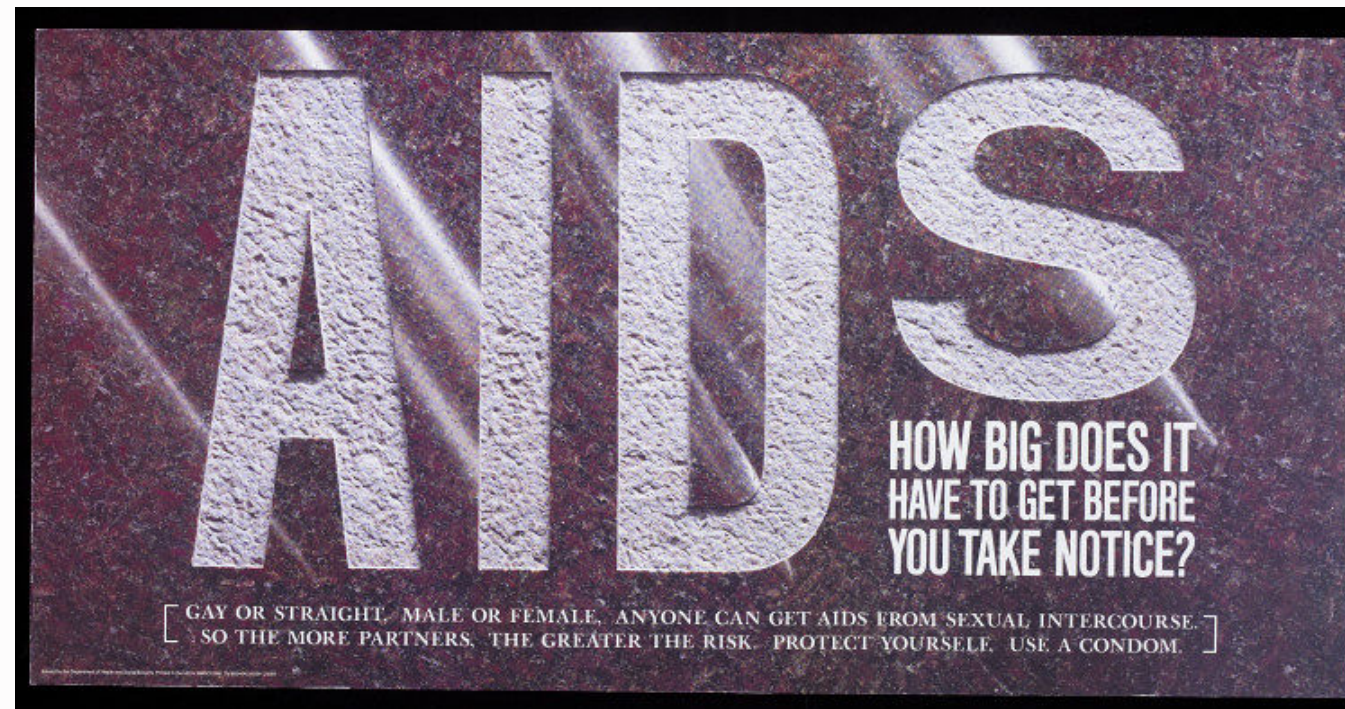
EILEEN NIXON, NURSE CONSULTANT HIV  
FUNGAI MURAU, RESEARCHER, ADVOCATE & ACTIVIST  
GILLIAN DEAN, CONSULTANT HIV/GU MEDICINE

# HIV in 2021

Why we need to end HIV  
Stigma



# AIMS OF THE PRESENTATION



## List of key updates

- HIV epidemic
- Progress towards ending HIV transmission
- The effect HIV stigma on people living with HIV
- Action plan to reach zero stigma in Brighton & Hove
- What YOU can do to help



# HOW HIV BECAME A MANAGEABLE LONG-TERM CONDITION





## **“AIDS is exceptional. The response to AIDS needs to be equally exceptional”**

**Dr Peter Piot, UNAIDS Executive Director. London, 8 Feb 2005**

"A mere disease, a disease that is not easily contagious, a disease that was a circumscribed epidemic just 25 years ago, has morphed into a pandemic of cumulatively over 65 million people! And this pandemic will continue to expand for decades!"



“Putting **15 million people on treatment** in 15 years was a dream. Today, it's a reality.”

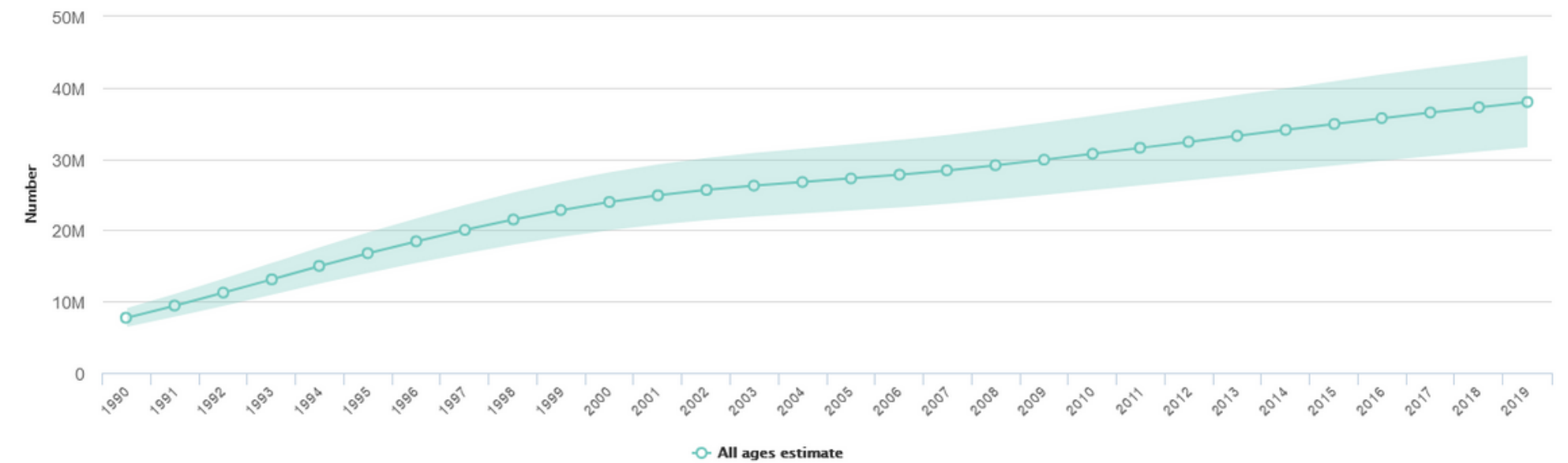
Michel Sidibe,  
Executive Director, UNAIDS

**#AIDS2016**



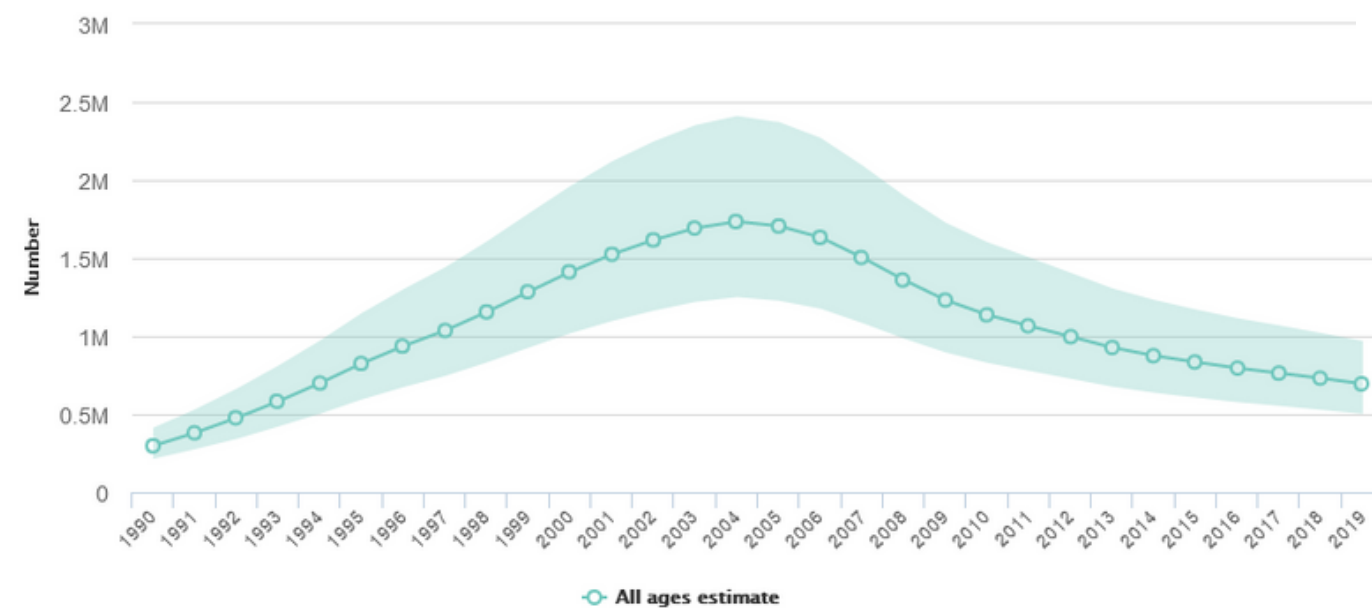
# RISING NUMBERS OF PEOPLE LIVING WITH HIV

People living with HIV (all ages)



Source: UNAIDS epidemiological estimates, 2020

Trend of AIDS-related deaths

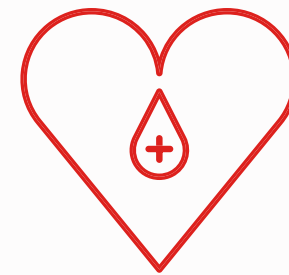


Source: UNAIDS epidemiological estimates, 2020

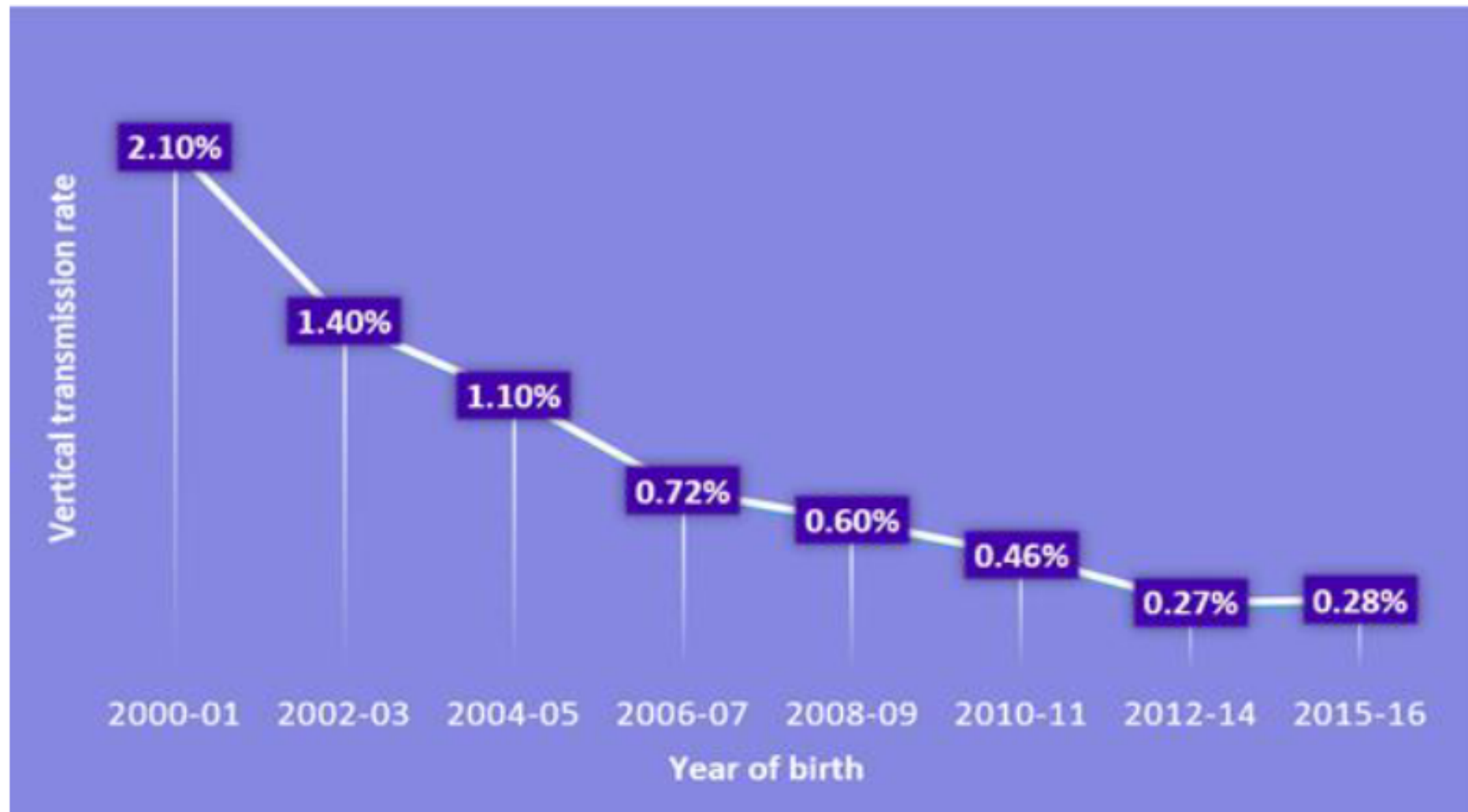
Change in AIDS-related deaths since 2010

**-39 %**

# MOTHER-TO-CHILD TRANSMISSION



## Vertical transmission in UK/Ireland, 2000-2016



Data for 2000-11 from Townsend *et al.* AIDS 2014; data for 2012-14 from Peters *et al.* CID 2016; data for 2015-16 from Peters *et al.* HIV Drug Therapy Glasgow 2018


**Link to National Surveillance of HIV in Pregnancy & Childhood (NSHPC) [here](#)**





# HIV TREATMENT AS PREVENTION

Effective HIV treatment ensures you can't pass it on




On effective treatment you can't pass it on

HIV drugs are now so effective that the virus is untraceable in the blood stream. This is known as undetectable. This means people with HIV on effective treatment can't pass it on to their partners. In Brighton & Hove 99% of people living with HIV are on effective treatment and unable to pass it on.

Undetectable = Untransmittable  
U=U

Having intimate relationships is completely safe. Find out more at [www.themartinfisherfoundation.org](http://www.themartinfisherfoundation.org)



Donnell D, Baeten JM, Kiarie J et al. Lancet 2010. Cohen MS, Chen YQ, McCauley M et al. N Engl J Med 2011. Rodger AJ, Cambiano V, Bruun T, et al. JAMA 2016. Rodger AJ, Cambiano V, Bruun T, et al. Lancet 2019.



U=U

UNDETECTABLE  
=  
UNTRANSMITTABLE

A PERSON LIVING WITH HIV  
WHO HAS AN UNDETECTABLE  
VIRAL LOAD DOES NOT  
TRANSMIT THE VIRUS TO THEIR  
PARTNERS.

The International AIDS Society is proud to endorse the U=U consensus statement of the Prevention Access Campaign.

IAS

[The Lancet HIV 2017 4, DOI: \(10.1016/S2352-3018\(17\)30183-2\)](#)



# OCCUPATIONAL EXPOSURE TO HIV

HIV transmission from a patient to a healthcare worker is very rare. If the HIV patient has an undetectable viral load, Post Exposure Prophylaxis (PEP) is **NO LONGER INDICATED**

## Universal precautions for handling blood & bodily fluids

There are no additional infection control measures required to look after a person with HIV unless they have another infection that requires additional infection control measures /PPE

## Gloves and aprons are NOT required

When there is no potential for exposure to blood or bodily fluids



# LIVING WITH HIV TODAY





# CURRENT CHALLENGES FOR PEOPLE LIVING WITH HIV

**While many people living with HIV are well and stable, many also face the following issues:**

- ageing faster than general population, increasing co-morbidities / multi-morbidity
- higher prevalence of mental health issues
- social isolation due to death of many peers
- transition from paediatric to adult care
- increasing homelessness / recreational drug use / financial hardship / unemployment
- difficulty remaining engaged with HIV treatment and care for life
- stigma and discrimination



# ENDING HIV TRANSMISSION



# ENDING THE HIV EPIDEMIC

## BY 2030



PARIS DECLARATION  
1 December 2014  
(amended 24 July 2018)

### FAST-TRACK CITIES: ENDING THE AIDS EPIDEMIC

Cities achieving the 90–90–90 targets by 2020

Fast-Track Targets	
by 2020	by 2030
<b>90-90-90</b> <small>Treatment</small>	<b>95-95-95</b> <small>Treatment</small>
<b>500 000</b> <small>New infections among adults</small>	<b>200 000</b> <small>New infections among adults</small>
<b>ZERO</b> <small>Discrimination</small>	<b>ZERO</b> <small>Discrimination</small>



Diagnosed



On treatment



Virally suppressed



Good health-related  
quality-of-life

# BRIGHTON & HOVE

## Fast-track cities: Ending the AIDS epidemic

Cities achieving 90–90–90  
targets by 2020

Paris declaration 1 Dec 2014

## Brighton & Hove Fast track city 2019

94%

99%

99%

and aiming for zero discrimination!







CLICK HERE FOR  
FULL REPORT!

## Twenty point action plan – first four tackling HIV stigma & discrimination

**ACTION 1:** All national and local HIV treatment and prevention initiatives should explicitly plan and evaluate how they will address HIV-related stigma, discrimination and health inequalities

**ACTION 2:** Training on HIV and sexual health should be mandatory for the entire healthcare workforce to address HIV stigma and improve knowledge of indicator conditions

**ACTION 3:** Implement a programme of coordinated national campaigns across the decade, aiming to enable residents in England to know how to find out their HIV status and increase their awareness of combination HIV prevention

**ACTION 4:** Opt-out rather than opt-in HIV testing must become routine across healthcare settings

# **WHAT IS HIV STIGMA AND DISCRIMINATION?**



# HIV STIGMA DEFINITIONS

## **Self or internalised stigma**

Acceptance of negative self-beliefs associated with having HIV

## **Anticipated or perceived stigma**

Negative beliefs and expectations of treatment/care

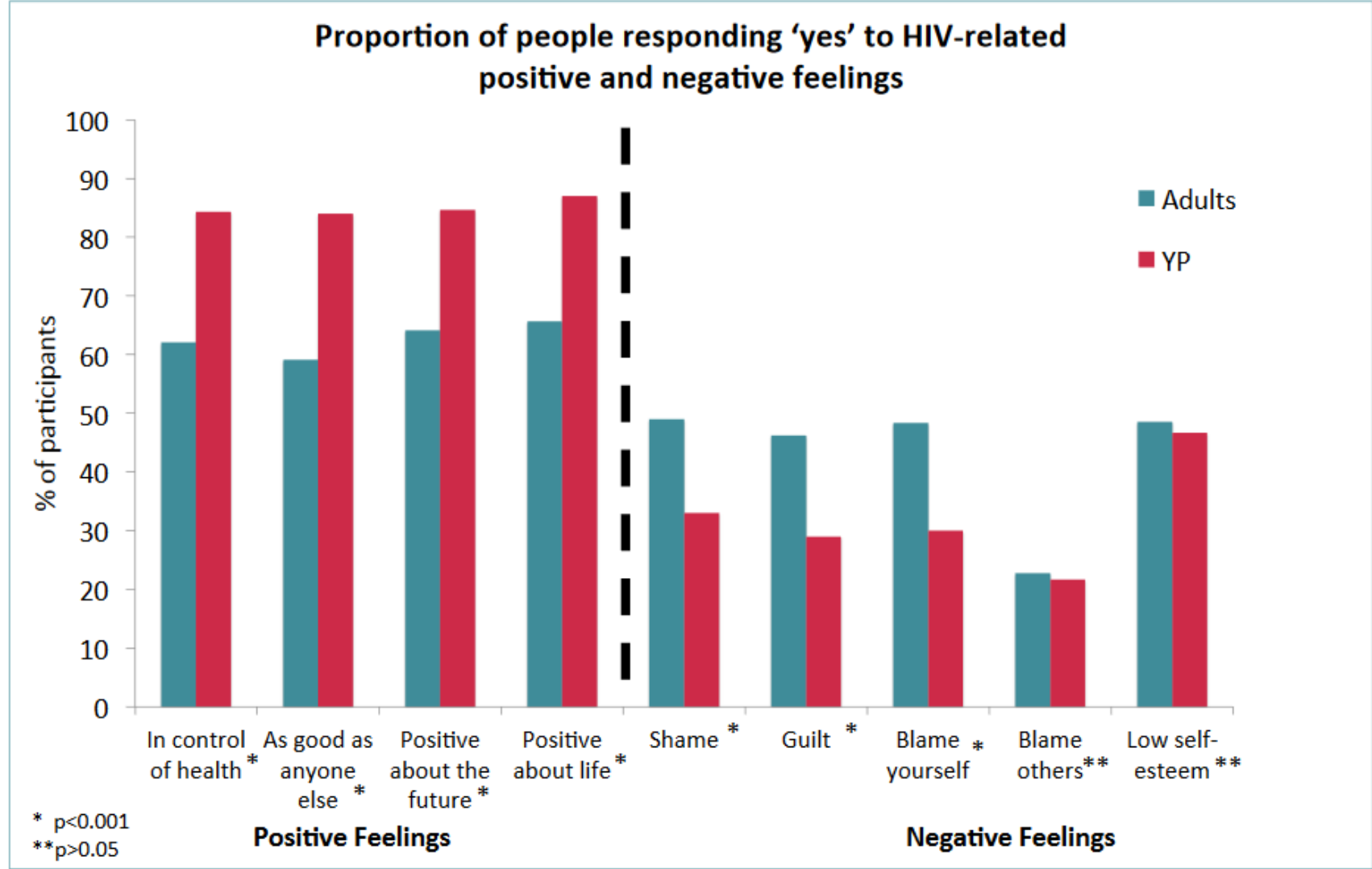
## **Discrimination**

Negative and devaluing treatment of people due to their HIV status



# SELF IMAGE

An intergenerational comparison of positive self-image across the UK  
*The Young People Living with HIV Stigma Survey UK 2017*

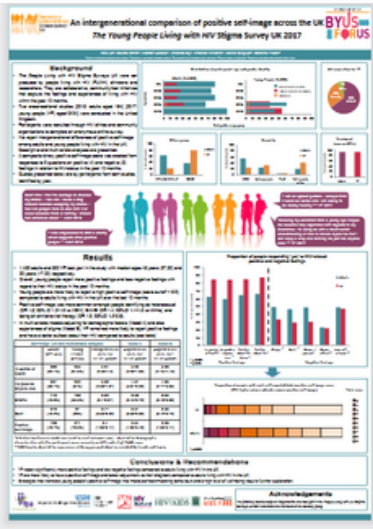


1,450 adults and 300 YP took part in the study

- median age adults 45 years (37,52)
- median age YP 20 years (17,22)

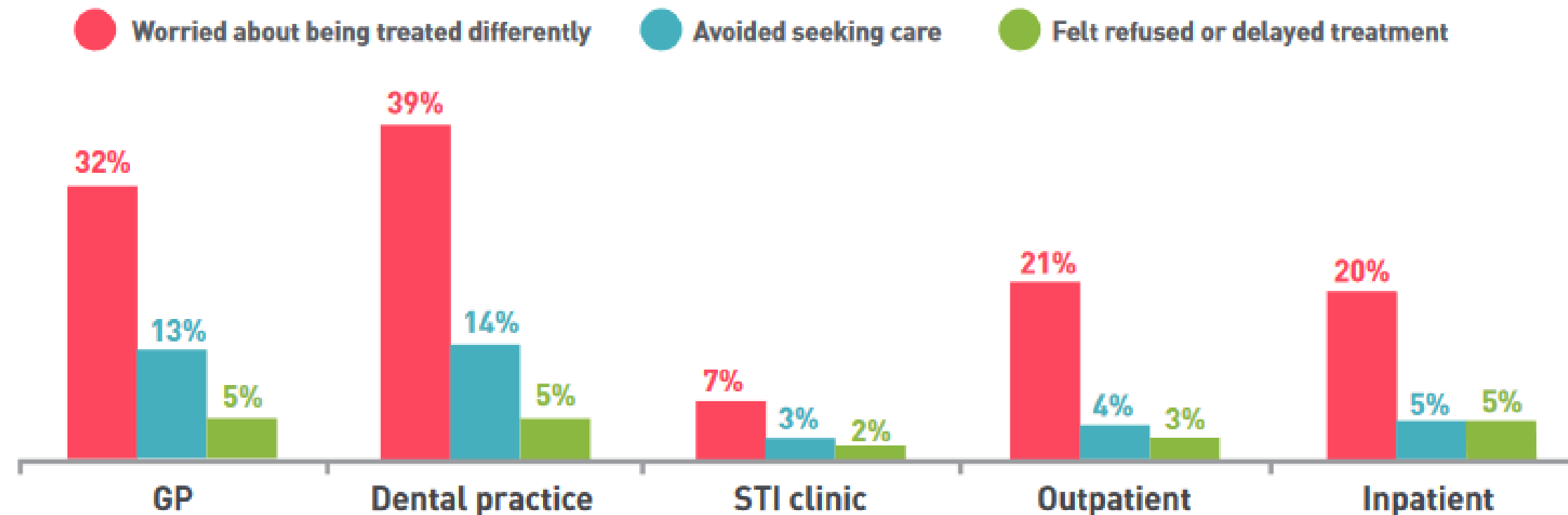
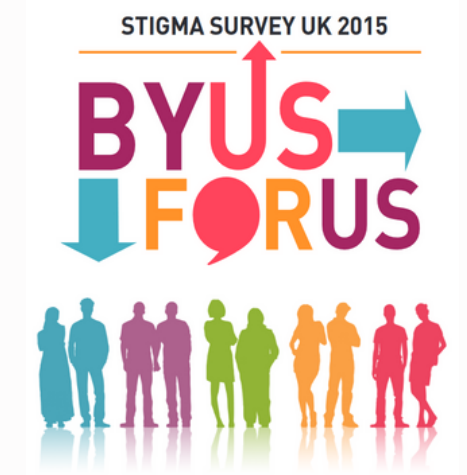
In the last 12 months, have you experienced the following in relation to your HIV status?	
Felt suicidal?	18%
If diagnosed HIV positive in the last 12 months, felt suicidal?	28%

CLICK HERE FOR FULL POSTER!





# HEALTHCARE SETTING EXPERIENCES



Heard negative comments from a healthcare worker about your stats or other PLWH	13%
Felt there was excess attention to using barrier protection e.g. gloves, masks	21%
Been given the last appointment of the day, not by choice	12%

CLICK HERE FOR  
FULL UK REPORT!



HIV in the UK: Changes and Challenges; Actions and Answers  
The People Living With HIV Stigma Survey UK 2015  
National findings

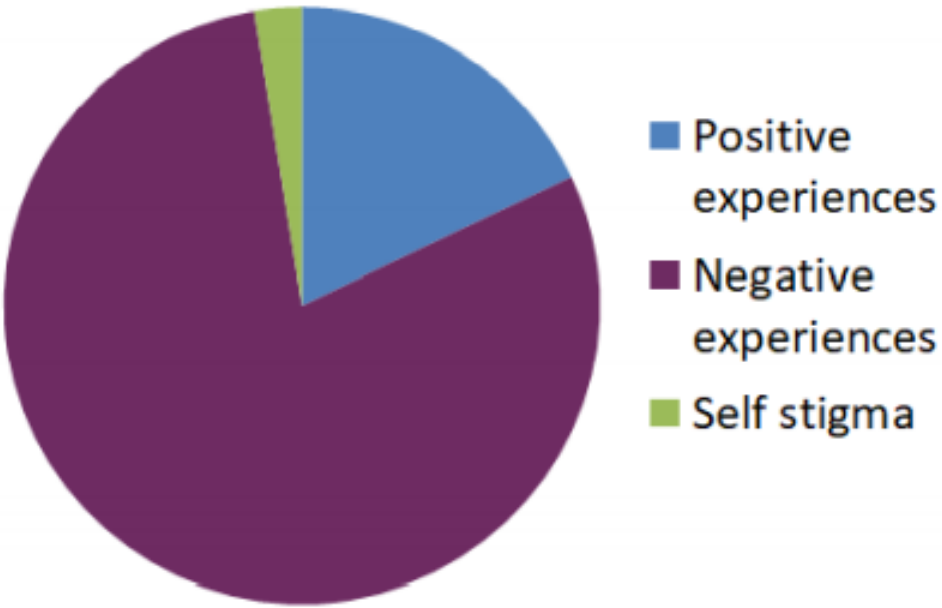
# **HIV STIGMA & DISCRIMINATION IN BRIGHTON AND HOVE**



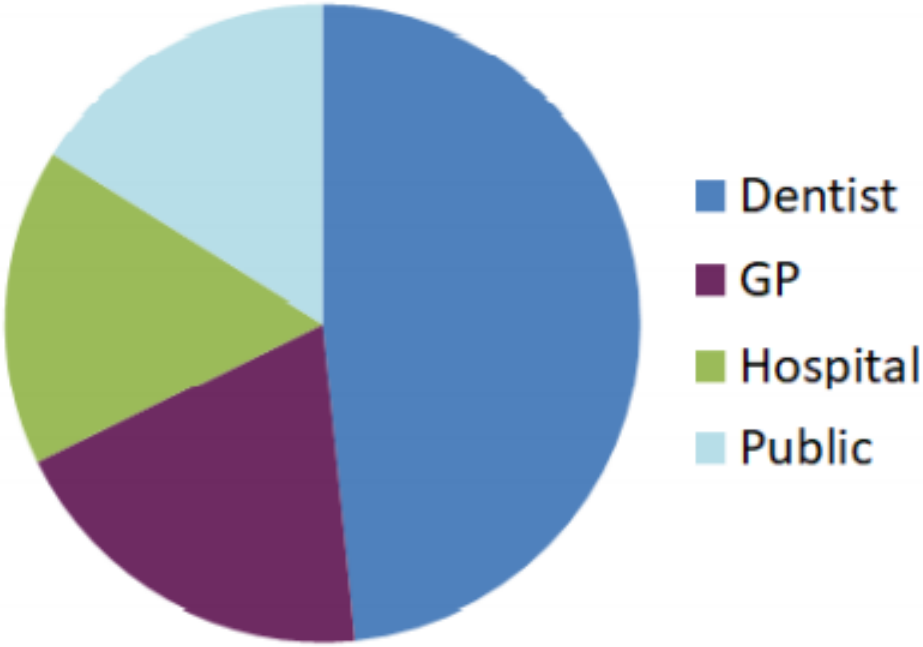
# BRIGHTON & HOVE

## STIGMA DATA

Experiences of stigma & discrimination



Negative Experiences



*Positive Voices Survey 2017 – Brighton and Hove qualitative data*



# Examples from Brighton & Hove data

“When I attended my GP she made me feel very upset because instead of reading my notes to find out that I contracted my HIV from my ex who I was with for a long time and had 2 children with she came straight out and asked if I contracted it by sleeping around.”

“The last 3 times I have been at xxxxxx they have been nasty. On one occasion I was asked because they could see my medical records that I used to, nearly 2 years ago, use party drugs. Three times I was asked 'so are you HIV positive because you shoot up?' and all in front of other patients”.

“A (dental) hygienist at xxxxx Practice victimised me and then refused to treat me because of my HIV status.”

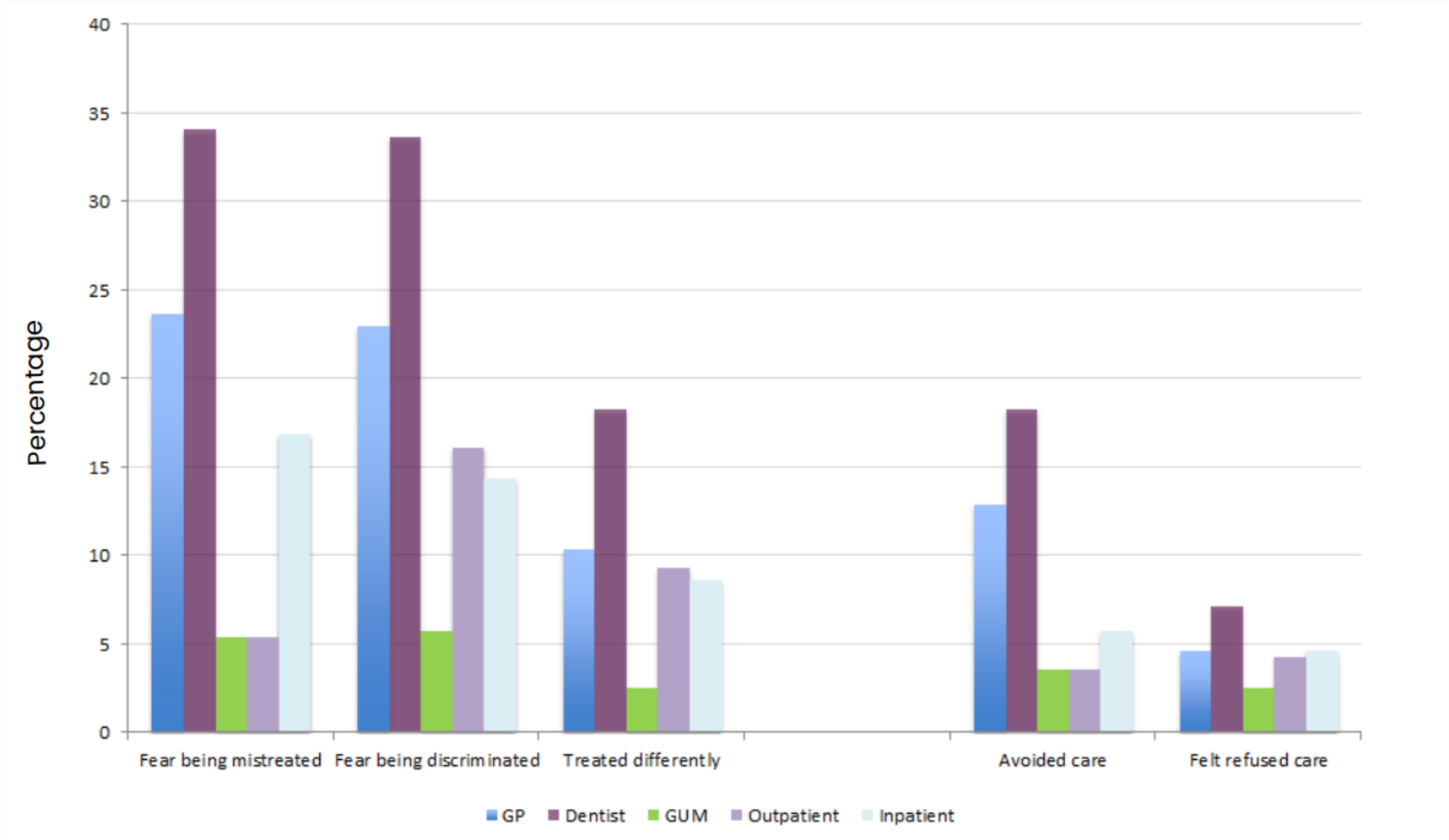
“I was refused cosmetic surgery 4 years ago – consultant said HIV patients are too high risk for cosmetic surgery”.





# SOUTH EAST ENGLAND

## STIGMA EXPERIENCES



People living with HIV stigma index 2015: South East data

# **WHY IS HIV DIFFERENT FROM OTHER LONG-TERM CONDITIONS?**



# STIGMA IN OTHER LONG TERM CONDITIONS

## Diabetes

- patients surveyed in US in 2017
- n=12,000
- 78% Type 1 and 52% type 2
- avoidance of disclosure
- fear of judgement or blame

Liu, N. Brown, A. Folias, A. et al. 2017.  
Browne JL, Ventura A, Mosely K, Speight J. 2013

## Epilepsy

- 10,000 tweets
- relating to epilepsy
- 40% were derogatory

McNeil, K. Brna, PM KE Gordan 2011

## Lung cancer

- higher stigma scores compared to breast or cervical cancer

Marlow, L. Waller, J. Wardle, J. 2015



# **WHY SINGLE OUT HIV STIGMA NOW**

**HIV is a blood borne  
virus that is largely  
sexually transmitted**

**High levels of  
engagement in  
treatment and  
care are central to  
managing the HIV  
epidemic**

**The end of HIV  
transmission is really  
within our grasp**





# **WHAT YOU CAN DO TO STOP HIV STIGMA AND DISCRIMINATION**





# BRIGHTON & HOVE CITY-WIDE ACTION PLANS

## Reducing stigma among healthcare workers

- Stigma reference slides for all Trust presentations
- Stigma education resource pack
- "10-things I wish you knew" teaching tool
- Rollout to primary care/dentists

## Empowering people living with HIV

- Building resilience
- 1-1 mentoring
- Work with MIND charity "for better mental health"

## Community engagement

- Work with local business
- Build on public awareness campaign
- Repeat knowledge/attitudes survey
- MFF HIV information bus



# THE BEGINNING OF THE END OF HIV STIGMA



- Reflect on your own perceptions /judgements of people living with HIV
- Use universal precautions appropriately when handling blood and body fluids
- Challenge prejudice or discriminatory behaviour towards people with HIV
- Be mindful that some people with HIV may have self-stigma or anticipated stigma and may interpret your actions differently than you intended
- Show your family and friends the Brighton & Hove public awareness campaign [here](#)
- If you would like to get involved please contact [eileen.nixon1@nhs.net](mailto:eileen.nixon1@nhs.net) or [gillian.dean2@nhs.net](mailto:gillian.dean2@nhs.net)



## ... AND REMEMBER



HIV isn't  
scary  
anymore

Now we have effective treatment, HIV has become like many other medical conditions. By taking as few as one tablet a day the virus is completely controlled and cannot be passed on. People diagnosed early with HIV and started on treatment can remain fit and well, and live as long as anyone else. HIV treatment has moved on... we should too!

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