#### **Opening of the Forum**

#### Stigma & Discrimination in Europe

#### Vanessa Apea

Barts Health NHS Trust / Queen Mary University of London, United Kingdom









# Stigma and Discrimination in Europe

#### Dr Vanessa Apea

Consultant Physician in Sexual Health and HIV, Barts Health NHS Trust Honorary Senior Lecturer, Queen Mary University of London Clinical Representative, Stigma Subgroup, FTCI London





## Defining Stigma

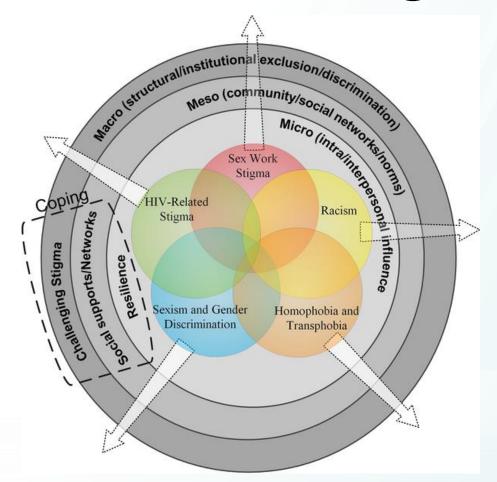
- Complex social phenomenon
- "Involves distinguishing people based on social statuses (such as attributes, illnesses and identities) and socially devaluing, discrediting and excluding individuals with those statuses"
- HIV remains a highly stigmatised and misunderstood health condition
- Stigma undermines all we do in the HIV sector and is the most ubiquitous challenge to successful HIV prevention, treatment, and care
- A clear social justice issue







## Intersectional Stigmas



Logie CH, James L, Tharao W, Loutfy MR (2011) HIV, Gender, Race, Sexual Orientation, and Sex Work: A Qualitative Study of Intersectional Stigma Experienced by HIV-Positive Women in Ontario, Canada. PLoS Med 8(11): e1001124.

- HIV disproportionately affects those groups typically stigmatised in society
- Socio-structural factors and social determinants of health impact HIV transmission and HIV-related stigma.
- HIV-related stigma is closely related to societal power structures and frameworks
- PLWH often encounter intersectional stigmas – a convergence of multiple stigmatised identities







## London's Response

- The City of London has made its **commitment clear** to be the first city globally to get to **zero**.
- One of the greatest challenges is stigma.
- Fast Track Cities London spearheaded a systematic, collaborative approach to tackling stigma.
- Clear need:
  - for impactful interventions that will make a difference.
  - to understand where they were starting from to co-design these interventions.





## Path to achieving zero stigma

• Need: Dedicated action plan informed by real time evidence.

#### • Response:

- Early 2019 Dedicated funding identified and a stigma working group formed.
- Pragmatic review of evidence to date.
- Three key areas of focus proposed:

### INTERNALISED STIGMA:

Create an
empowerment
programme shaped by a
community of practice

## STIGMA IN THE NHS & OTHER PUBLIC SERVICES:

Create an HIV-friendly charter

#### **SOCIETAL STIGMA:**

Commission a survey to set a baseline on public's knowledge and attitudes towards HIV







## Tackling societal sigma

#### Early 2019:

Funding identified

Stigma Working Group formed

#### March 2020:

Stigma subgroup paused January 2021:
NAT and
Britain Thinks
commissione
d to develop a
public
knowledge
and attitudes
survey













#### December 2019:

Draft action plan shared for consultation

#### **August 2020:**

Action plan refreshed for a post-COVID London

#### July 2021:

Survey results published









Britainthinks
Insight & Strategy

# HIV: Public knowledge and attitudes

Our new report on public perceptions and knowledge of HIV in the UK





HIV: Public knowledge and attitudes, National AIDS Trust and Fast-Track Cities London,

July 2021, nat.org.uk/files/hiv-public-knowledge-and-attitudes-pdf







## Methodology

#### Community stakeholder consultations

3 x stakeholder roundtables

Aimed to bring in expert opinion to inform other stages of the research and increase community involvement in the project

#### Exploratory focus groups

2 x focus groups with the general public

Aimed at supporting survey design

Explored where public perceptions come from, understanding of HIV and language used by public when talking about HIV

#### Quantitative research

Nationally representative online survey

Generated robust statistics on understanding and awareness of HIV

#### Deep dive focus groups

4 x focus groups

Explored key themes from the survey findings with specific population groups

Selection of these groups informed by preceding phases of the research

18 - 27 Jan 2021

4 March 2021

16 - 22 April 2021

26 May 2021

#### A deep dive into London







Over 6 in 10 report not having heard anything about HIV in the last 6 months



A lot of the adverts on TV and radio are about mental health and cancer, and don't really concentrate on this at all. There's not much awareness or education.

> Black participant, 35-64, Birmingham

More likely to say they have not heard anything about HIV in the last six months are:

- those aged 65+ compared with those aged 34-64 and those aged 18-34 (77% vs. 64% and 51% respectively)
- C2DEs compared with ABC1s (70% vs. 58%)
- non-Londoners compared with Londoners (66% vs. 47%)
- White people and South Asian people compared with Black people (66% and 67% vs. 40%)

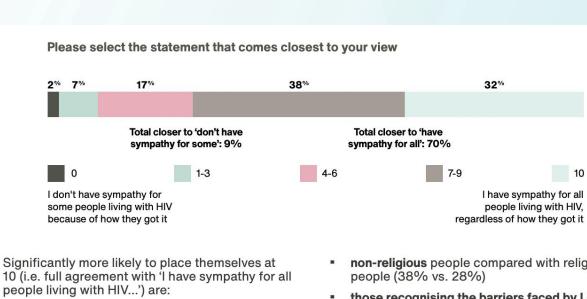
- those in rural areas compared with those in urban areas (69% vs. 62%)
- heterosexual cisgender people compared with gay and bisexual men and LGBT people (66% vs. 43% and 45%).
- those with low social media usage compared with those with high usage (77% vs. 53%)
- tabloid readers compared with broadsheet readers (59% vs. 49%).







## Only 1/3 of Londoners say they have sympathy for **PLWH** regardless of how they acquired it



- LGBT people compared with heterosexual cisgender people (48% vs. 31%)
- those who personally know someone with HIV compared with those who do not (46% vs. 31%)
- Black people compared with White people and South Asian people (39% vs. 32% and 14%)
- women compared with men (36% vs. 28%)

- non-religious people compared with religious
- those recognising the barriers faced by LGBT people compared with those who do not (38% vs. 27%)
- broadsheet readers compared with tabloid readers (40% vs. 27%)
- those with high / higher than average and middling knowledge of transmission compared with those with lower than average knowledge (41% and 36% vs. 19% with low knowledge).

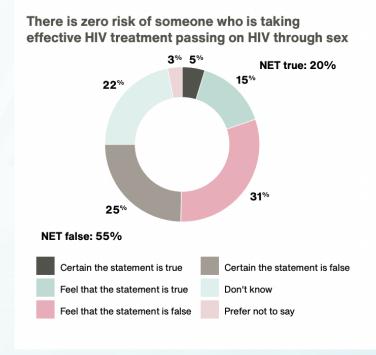
It should be noted that 64% of the public placed themselves at 0-9 on the scale, indicating their sympathy for someone with HIV would be qualified / that they could think of instances in which they would not have sympathy for all living with HIV.







# Public awareness of 'U=U' is low, with a majority believing that it is false that effective treatment prevents transmission



A majority believe that it is false that effective treatment prevents transmission. Awareness of U=U is *highest* in London amongst:

- those aged 18-34 compared with those aged 35-64 and 65+ (26% true vs. 17% and 14% respectively)
- gay and bisexual men compared to heterosexual cisgender people (52% true vs. 19%)
- those who know someone living with HIV compared to those who don't (34% true vs. 17%).





# HIV stigma complex – but 3 key themes emerged

#### 5.2 Attitudes to people living with HIV

#### **Key findings**

- 1 Generally, the public believe those living with HIV deserve the same support and respect given to those with other health conditions. Participants strongly felt that society is now more positive towards those living with HIV than in the past.
- Nevertheless, stigma towards people living with HIV continues to persist deep in society. There is an appreciation among the public that negative judgements exist and that these may be felt by people living with HIV towards themselves (selfstigma). Qualitatively, many imply being scared
- to say 'the wrong thing' for fear of perpetuating stigma and some expressed views that they may not have been aware were potentially stigmatising.
- 3 HIV stigma is complex but there were three key themes that emerged: the link between HIV and broader taboo behaviours (condomless sex and intravenous drug use), low knowledge of how HIV can be transmitted (leading to differential treatment) and homophobia (with associations between HIV and the LGBT community still strong for many).

Acquiring HIV is associated with 'taboo' behaviours, including condomless sex, promiscuity and intravenous drug use

Low knowledge of transmission, treatment and outcomes

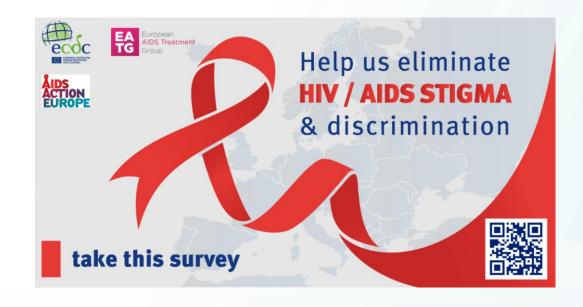
Negative attitudes towards LGBT community, who are closely associated with HIV.







## European Insights



Noori T. Measuring HIV-related stigma in the community and in healthcare settings: Preliminary results and future plans

- European Centre for Disease
   Prevention and Control, European
   AIDS Treatment Group, AIDS Action
   Europe, and UK's National AIDS
   Trust: First ever European-wide
   HIV stigma survey
- Explored the experience of stigma amongst people living with HIV across Europe and Central Asia
- Preliminary results presented 14 th October 2022 – EACS Standards of Care meeting





## European Insights

- November 2021 January 2022: 3272 responses
  - 54 countries
  - 80% men, of these 0.5% trans men 16% women, of these, 17% were trans women 3% non-binary or identified in some other way, 1.5% did not respond
  - 68% identified as lesbian, gay or bisexual.
  - 90% on ART
- PLWH in Europe are as likely to have experienced stigma in recent years as a decade ago
  - Particularly in healthcare settings anticipated stigma ++
  - Questioned re: whether ashamed of their HIV status and if low self-esteem because of status
    - 27-28% agreed or strongly agreed with both questions
    - 45-49% disagreed or strongly disagreed with them
  - 17% of respondents saying they had not told even one friend about their HIV status







## Advancing towards zero

- Real time evidence that stigma is prevalent with insight into the key drivers.
- Next steps: ACTION!
  - Translating key learning from the stigma survey into an action plan to mitigate/eliminate stigma with defined metrics of success.
    - e.g healthcare provider surveys and charters
- Two of the key areas of focus/reflection:
  - Language
  - U=U messaging





## Acknowledgements

- Fast Track Leadership Group
- Fast Track Stigma Subgroup
  - Jess Drummond
  - Pahlia Kenny
  - Kat Smithson
  - Hamza Husseini
  - Steve Worrall
  - Garry Brough
  - Alastair Hudson
  - Maria Vidal Read
  - Jemma Gilbert
  - Meaghan Kall
  - Clive Grimshaw

#### Fast Track Stigma Subgroup

- Alison Pearce
- Natalie Priestley
- Sara Paparini
- National AIDS Trust
- Britain Thinks







## THANK YOU

