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Stigma in the NHS

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In relation to this presentation I declare that I have no conflict of interest

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What to cover on the session

- Why people living with HIV are stigmatised
- Impact of stigma on people living with HIV
- What interventions work in reducing and or eliminating stigma
- How do we gather evidence to support the interventions
- Nurses role and MDT in eliminating stigma

HIV in the United Kingdom

- The UK has a relatively small HIV epidemic with an approximately 106,890 people living with HIV
- Largely concentrated among certain key populations: men who have sex with men and black Africans, people who use drugs
- 2014 survey among black Africans living with HIV reported that a third had been discriminated against because of their HIV status. Half of this number said they had been discriminated against by healthcare workers (including doctors, dentists and hospital staff).
- Late diagnosis remains a challenge: 42% (640 out of 1540 in 2020 – England) of diagnosed happened at a late stage.
- UK has made a significant progress in antiretroviral treatment coverage in the recent decades: 91% of people living with HIV are virally suppressed
- Awareness and knowledge continues to drop: only 45% of the population know about HIV

<http://www.nat.org.uk/media/Files/Publications/NAT-African-Communities-Report-June-2014-FINAL.pdf>

https://www.nat.org.uk/sites/default/files/publications/Mori_2014_report_FINAL_0.pdf

<https://www.gov.uk/government/statistics/hiv-annual-data-tables>

STIGMA

- *“The shame or disgrace attached to something regarded as socially unacceptable.”*

Internal

(self, perceived, experienced)

External

(workplace, healthcare setting, and religious sector)

Indirect

(towards those caring for people living with HIV)

'HIV: Public Attitudes and Knowledge' 2021 Key Findings



Most of the public don't hear or think about HIV much

Sexual health isn't a front-of-mind concern for most people

Knowledge of HIV is patchy including latest developments on U=U

Knowledge is especially low in South Asian community, taboos on discussing sex and STIs

HIV continues to be seen as a serious health condition by the public

Most of the public say they are empathetic towards those living with HIV and deserve the same level of support and respect as with other long-term conditions

Stigma towards those with HIV continues to exist and is felt to be deeply entrenched

Stigma is seen by many to be a result of the link between HIV and other taboo behaviors (condomless sex and intravenous drug use)

Most of the public say they are uncomfortable with having a sexual relationship with someone living with HIV

<https://www.nat.org.uk/publication/hiv-public-knowledge-and-attitudes>

What are stigmatizing behaviors and consequences



Studies from different parts of the world reveal that there are three main immediately actionable causes of HIV-related stigma in health facilities:

- Lack of awareness among health workers of what stigma looks like and why it is damaging;
- Fear of casual contact stemming from incomplete knowledge about HIV transmission;
- Association of HIV with improper or immoral behaviour.



Measuring health care HIV-related knowledge within our NHS Trust

- Knowledge about HIV (and U=U) remains poor in those not working in HIV
- In a survey of 411 staff working at St Bartholomew's Hospital, the Royal London Hospital and Newham Hospital:
 - The respondents were predominantly nurses (57%), healthcare assistants (19%) and doctors (12%)
 - working in adult medical, surgical and critical care wards, accident & emergency and theatres.
 - Three-quarters would not be confident discussing HIV status with a patient. A quarter would isolate
 - HIV-positive patients in side-rooms and half thought they should be operated on at the end of the day, due to a risk of contamination.

- 80% had not heard of U=U.
- 35% did not think that a person living with HIV can conceive and have children who are HIV negative.
- 38% felt at risk of acquiring HIV when treating people living with HIV
- 76% were not confident discussing HIV with patients
- 82% said they would like more information and training on HIV

Shongwe M et al. Measuring healthcare HIV knowledge within our NHS Trust. British HIV Association conference, abstract O06, November 2020

Healthcare professionals' comments on survey questionnaire

I feel nervous taking blood from HIV patients!

U=U - What is that anyway? I have never heard of this!

Why complete this, it does not affect me!

“Stigma and discrimination are amongst the foremost barriers to HIV prevention, treatment, care and support”

UNAIDS 2014 Guidance Note Reduction in HIV related stigma and discrimination and Kings Fund Report (2017)

“...If we do not appreciate the nature and impact of stigma, none of our interventions can begin to be successful. AIDS is probably the most stigmatised disease in history.”

Edwin Cameron

Legislating an epidemic: the challenge of HIV/AIDS in the workplace. 2007. ILO

Nurses role in reducing stigma

- Specialist HIV nurses: Act as role models and display positive attitude toward people living with HIV and raising awareness
- General nurses: Non-judgmental care, standard precautions and challenging prejudice.
- Nurses Education play an important role in HIV stigma reduction
- HIV health care staff educate their patients, colleagues, and the public to help counter stigmatism.
 - Giving accurate information to stop stigmatising or display of negative attitudes towards people living with HIV. E.g. U=U
 - Assist those living with HIV who self stigmatise through education, promotion of self management strategies and encouragement to let go of negative judgments about what it means to be HIV positive.

Supporting HIV service to reduce stigma

- National survey looking at healthcare professionals HIV knowledge



Independent HIV Commission, HIV Oversight Group; government, civil society, bilateral and multilateral donors, academia, all disciplines supporting people living with HIV including NGOs

Strategies on stigma elimination

- HIV Action Plan set out our commitment to zero new transmissions of HIV by 2030
 - Objective 4: improving quality of life for people living with HIV and addressing stigma
 - We will tackle stigma and improve knowledge and understanding across the health and care system about transmission of HIV and the role of treatment as prevention, by enhancing the training of the health and care workforce and drawing on the best of innovation on public awareness and health promotion.
 - Effective alliance with all potential collaborators and partners.
- Education and training (Hospital, primary health care and Universities)
 - Share game changing message U=U
 - Adherence and quality of life
- Normalisation of HIV Testing and prevention
 - A&E testing
 - PEP and Prep (includes marginalised group)
 - Family and faith, love and sex, keeping health, food and going out
- Share Positive Voices results with wider NHS
 - Local Action plan
- Other initiatives
 - Fastrack cities: Charter for NHS organisations to sign up
 - Media campaigns, posters and other public edutainment

Conclusion

- Reducing HIV-related stigma is a vital component of HIV prevention and retention in care
- Our results show that knowledge of HIV transmission, U=U, and prevention is low amongst healthcare professionals and hospital workers in our Trust
- Raising awareness of what stigma is and the benefit of reducing it, also addressing fears and misconception about HIV Transmission.
- Adoption of regular HIV update in the NHS and possibly consider National Guidance on HIV STIGMA by NICE
- HIV services to support national surveys distributions in creating evidence to support their local services with intelligence

Thank you