#### Primum Non Nocere – The Urgency of Eliminating Stigma in Health Settings

Laura Ferguson, PhD Program on Global Health and Human Rights Institute for Global Health, University of Southern California



### Political commitments to address stigma in health settings

- 2030 Agenda for Sustainable Development: "Leave no one behind"
- 2016 Political Declaration on Ending AIDS:
  - Promote non-discriminatory access to health care
  - Eliminate HIV-related stigma and discrimination by 2020
- UNAIDS strategy: target on eliminating HIV-related discrimination with a particular focus on health care



#### Stigma and discrimination: Definitions

- *Stigma* refers to beliefs and/or attitudes. Stigma is a dynamic process of devaluation that significantly discredits an individual in the eyes of others, such as when certain attributes are seized upon within particular cultures or settings and defined as discreditable or unworthy.
- *Discrimination* refers to any form of arbitrary distinction, exclusion or restriction affecting a person, usually (but not only) because of an inherent personal characteristic or perceived membership of a particular group. It is a human rights violation. In the case of HIV, discrimination can be based on a person's confirmed or suspected HIV-positive status.



## Manifestations of stigma and discrimination in health settings

- Denial of health-care services
- Provision of poorer quality care
- Physical and verbal abuse
- Mandatory HIV testing without consent or appropriate counselling
- Forced or coerced sterilization of women living with HIV
- Health providers minimizing contact with, or care of, PLHIV
- Requiring third-party authorizations for the provision of services
- Demands for additional payment for infection control
- Isolation of people living with HIV
- Lack of privacy
- Breaches of confidentiality



### Experiences of stigma and discrimination in health settings

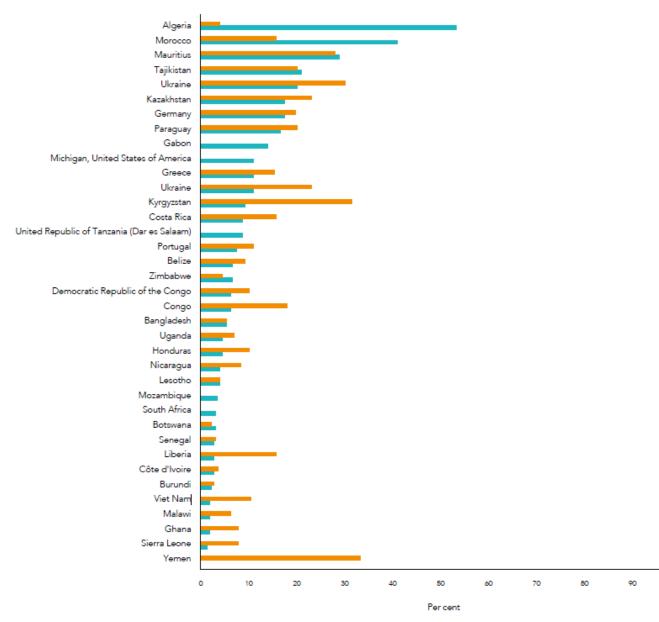
#### • Experiences of care:

- ¼ of PLHIV reported experiencing discrimination in health care
- 1 in 3 women living with HIV reported experiencing at least 1 form of discrimination related to their sexual and reproductive health in health care settings
- In 7 of 31 countries with accessible data, 1 in 5 people living with HIV reported that a health care worker had disclosed their HIV status without consent
- Denial of care:
  - 1 in 5 people living with HIV reported having been denied health care



Source: UNAIDS (2017) Confronting discrimination.

Percentage of people living with HIV who experienced discrimination in health-care settings, countries with available data, 2012–2017

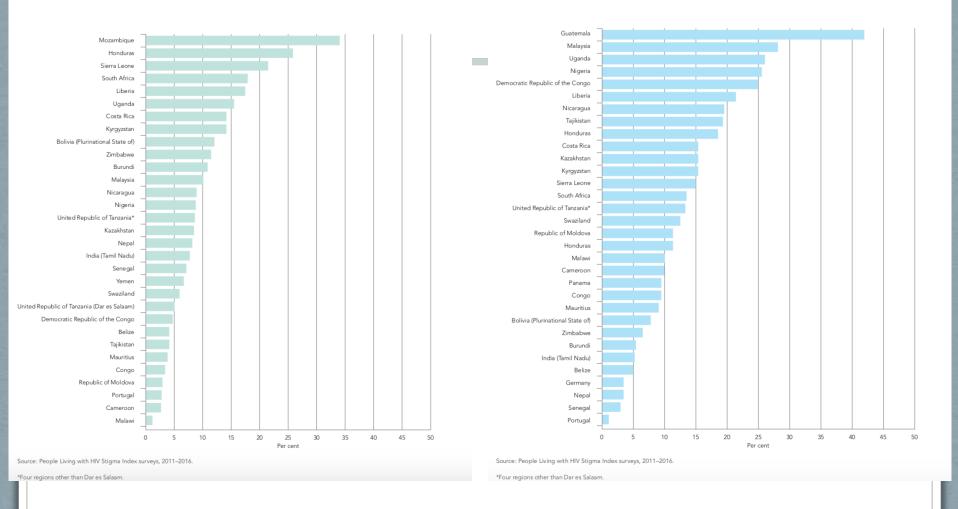


100

Source: People Living with HIV Stigma Index surveys, 2012-2017.

Figure 12. Percentage of people living with HIV who reported their ability to obtain antiretroviral therapy was conditional on the use of certain forms of contraception, countries with available data, 2011–2016

**Figure 13.** Percentage of women living with HIV who reported having been coerced by a health-care professional in the previous 12 months regarding method of giving birth because of HIV status, countries with available data, 2011–2016



Source: UNAIDS (2017) Confronting discrimination.

# Impacts of stigma and discrimination in health settings

- Discrimination in health settings is a violation of human rights
  - Right to health
  - Right to non-discrimination
  - Right to privacy
  - Right to liberty and security of the person
  - Right to freedom of expression and information
- Stigma and discrimination deter uptake of health services
- They impede achievement of UHC, 90-90-90 and epidemic control



Figure 2. Examples of stigma and discrimination that create gaps across the HIV testing and treatment cascade



# Impacts of stigma and discrimination in health settings

- Care seeking
  - 1 in 5 people living with HIV reported avoiding going to a local clinic or hospital due to HIV status (feared facing stigma and discrimination)
  - People living with HIV who perceive high levels of HIV-related stigma are 2.4 times more likely to delay enrolment in care until they are very ill
- Retention in care:
  - Coercive treatment and lack of confidentiality erode trust in services and reduce retention in care
- Treatment adherence:
  - Perceived discrimination in healthcare settings negatively impacts ART adherence, first through internalized HIV stigma, and then through depressive symptoms

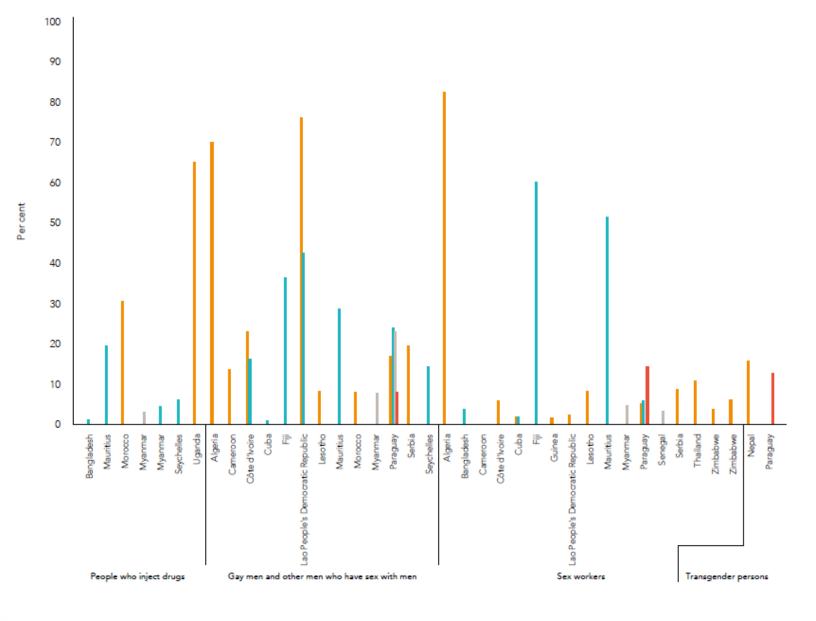


Sources: UNAIDS (2017) Confronting discrimination; UNAIDS (2018) Global AIDS Update; Turan, B. et al. AIDS Behav (2017) 21: 3431.

### Layering of stigma

- HIV status
- Gender
- Sexual orientation and gender identity/expression
- Engagement in drug use/sex work
- Age
- Poverty
- Immigration status GLOBAL HEALTH HUMAN RIGHTS

Percentage of key populations who reported having avoided health-care services in the past 12 months due to stigma and discrimination, countries with available data, most recent data, 2013–2017



Avoided health care 📃 Avoided HIV

Avoided HIV testing Avo

Avoided HIV-related care Avoided HIV treatment

# Impacts of stigma and discrimination in health settings

- Stigma and discrimination have a detrimental effect on health outcomes
  - Physical health
  - Mental health
- They negatively affect well-being and quality of life
  - Internalized stigma
  - Depression
  - Negative self-image
  - Disclosure concerns
- PROGRAM ON GLOBAL HEALTH HUMAN RIGHTS

# Drivers of stigma and discrimination in health settings

- Discriminatory laws and policies
- Discrimination is often driven by stigma negative underlying beliefs
- Stigma is rooted in communities and health workers come from these same communities
- Inadequate training and protocols
- Over-stretched systems and insufficient supplies



#### Stigma against health workers

- Health workers living with HIV
- Health workers providing services for people living with HIV
- Health workers providing services for key and/or vulnerable populations



# Addressing stigma and discrimination in health settings

- Continued measurement of stigma and discrimination in health settings and testing of effective interventions
- Legal protection against discrimination
- Health system strengthening: human resources, infrastructure, supply chain etc.
- Patients' rights education
- Capacity building on health workers' rights and responsibilities
- Functional and accessible mechanisms for redress
- Human rights-based, people-centred, health services **SLOBAL HEALTH** HUMAN RIGHTS SC INSTITUTE FOR GLOBAL HEALTH

### Rights-based, people-centred multi-sectoral action

- Human rights provide a useful framework
- Participation of people living with HIV and other key and vulnerable populations must be central
- Actions must be multi-sectoral
- Collaboration is key
- Build on existing experience... and tailor it to local settings



### Ongoing global initiatives

- Agenda for Zero Discrimination
  - 'Equal Health for All' virtual community of practice
  - www.ZeroHIVDiscrimination.com online repository of tools
- Global Partnership for Action to End All Forms of HIVrelated Stigma and Discrimination
- International Federation of Medical Students' Associations: Declaration of Commitment to Eliminate Discrimination in Health-care Settings (2016)
- People living with HIV Stigma Index
- Global AIDS Monitoring reports

#### **THANK YOU**

www.globalhealth.usc.edu/ghhr

laura.ferguson@med.usc.edu

