Graduating from missing linkages to value propositions to patient-centered approaches

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The Architecture of a Biomedical approach

• Access to speedy diagnostics & vaccines for HIV/TB epidemics

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• Everyone who required access to prevention, treatment and care services including the vaccines, receive it

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• **Sustainable Development Goals (SDG) target 3.3 on HIV:** “By 2030, end the epidemics of AIDS, tuberculosis, malaria & neglected tropical diseases and combat hepatitis, water-borne diseases and other communicable diseases” targets were met

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Would all these this be the END of HIV and TB co-epidemics?
Our lived reality...

Biomedical interventions are so advanced THAT...

➢ Treatment is Prevention and is easily accessible
➢ Genotype testing can identify HIV strains, ensuring effective & individualised treatment
➢ Viral load testing can suppress the virus & people living with HIV cannot transmit the virus
➢ People can adhere to less-toxic treatment, now live long & prosperous lives (i.e. are able to contribute to & benefit from society)

BUT....

• Our legal and policy environments pose barriers to access & criminalise people for hosting a virus or a bacteria
• People who need access to HIV, TB and sexual and reproductive health services (SRH) are left behind because they are deemed ‘unworthy’ of services

"Today, with over 35 million people living (and aging) with HIV and over two million becoming infected every year, we are faced with a new challenge: addressing morbidity and mortality from NCDs—heart disease, stroke, diabetes and metabolic complications, renal disease, cancers, liver disease, and mental illness—that increase with age and may be related to HIV and its treatment."
LACK OF INFORMATION ABOUT HIV CARE

LOW PRIORITY GIVEN TO HIV CARE
Matter of Fact

• Human rights responses are driven by enabling policy and legal environments

• The strategic combination of social mobilisation, science and use of the law led to access, but is no longer sufficient;

• Efforts need to mobilise communities to protect the rights of health care workers - to catalyze on their right to health through shared responsibility

• BUT the current frameworks cannot exist in a silo...with no implementation and effective monitoring of the ones who are most in need...

Pay less now, pay more later syndrome
Key Four “pressing threats” to Human Rights-based responses to HIV and TB

• Changing funding context and landscape, “HIV Fatigue”

• India “no longer the pharmacy of the South” – *International trade challenges hindering access to new medicines and commodities*

• Progressive guidelines in low-resource environments which cannot accommodate contextual realities (e.g. ‘Test and Treat’)

• Proliferation of criminal ‘sanctions’ toward certain people and disease(s):
  - Laws/ policies promote *child marriages*, but do not provide for ‘age of consent’ for accessing SRH services, incl. access to safe abortions
  - Laws/ Policies which refuse female primogeniture & proliferation of child-led households with no psycho-social support
  - State-sponsored stigma & discrimination through policies which force HCWs to provide access to certain persons
Risk vs. Accountability: The data paradox

• To galvanise action & address any public health problem, need to have a good estimate of the size of the population(s) at risk

• Easier for potential funders to neglect the at-risk populations if:
  - Data are unavailable
  - Basis of the estimates is not clear
  - Inconsistencies between estimates are not explained

• Governments argue for a more ‘culturally appropriate’ national definition of HIV-affected key populations that included less-controversial groups (long-distance truckers, fisher-folk)
  - Data on adolescents and young people living with HIV or TB are missing

• RESULTS of this push-and-pull between moral discourses, law enforcement, and public health evidence, is a ‘data paradox’ in which politically sensitive research is not done on key populations

“It is not just a paucity of data that leads to misinterpretation of the HIV epidemic. It is also a mind set, influenced by social conditioning and belief systems, related to internalized stigma and discrimination and to political pressures.”
Countries who have reported numbers on ART for 10–14 year olds through Global AIDS Monitoring, 2017

Data submitted in March 2017 for December 2016.
Source: UNAIDS, May 2017
70% of new HIV infections among children are in 10 countries

Source: UNAIDS 2017 estimates.
Missing linkages within health care delivery

• Governments do not prioritise “human rights” of public servants

• Increased occupational nosocomial Tuberculosis (TB) – A result of failed health care systems
  - Studies confirm that HCW 3X at higher risk of contracting TB than the general population. Some research points to 7X risk of contracting DR/ MDR-TB in high TB Burden countries

• Lack of structural planning (incl. increased human resources & salaries) during decentralisation proposals

• No legal protection of front-line workers, means that appreciation of patient-centered approaches by our governments; therefore front line workers are not protected

• CONSEQUENCE of abuse: Current crippling health care workers (HCW) and doctors strikes [i.e. Call to Action: improved working conditions & better salaries]
Value proposition: patient-centered care approaches

• Evolution of “patients’ rights” = response to widespread & often severe human rights violations in health settings

• Within our region, the conceptualisation advances a discourse in which patients protect the rights of health care workers (HCW)

• Appreciates the concept of ‘shared responsibility’ = “Ubuntu”

• Provides for opportunity related to “dual loyalty,” or a health provider’s “simultaneous obligations, express or implied, to a patient and to a third party, often the state”

• This approach, allow patients to be custodians of their own health response, by protecting their HCW
Business case: Minimum Service Level Agreement for Health care workers (MSLA)

**PURPOSE:** Protect the rights of the HCWs and those of the patient

- MSLA balances right to strike (in case of a labour dispute), with the right of access to health care services by guaranteeing some of the essential services.

- The norm in Western countries guarantee the right to strike to employees.

**BENEFITS:**

(i) A MSLA will ensure that during any time of turmoil, a minimum level of emergency services are provided in a controlled and amicable manner.

(ii) HCWs do not spend years of training, often at great personal and financial expense, to spend their time protesting - such action is undertaken as an absolute last resort when all other avenues of resolution have failed.

(iii) Often open doors to legally protected protest in a controlled manner after the comprehensive dispute resolution process.
Value proposition: FIND, TREAT and CARE for Children, Adolescents & Youth

- Adolescent and Youth friendly programming requires provision of an enabling policy and legal environment

- Programmatic design and roll-out of interventions must be ‘youth and adolescent-led’

- Revision of *Greater involvement of people living with HIV (GIPA)* and *meaningful involvement of people living with HIV (MIPA)* principles, to support such programming

- ‘Youth Disclosure Guidelines’ for Counsellors/ Psychologists need to be part of a comprehensive Prevention, Access, Treatment and Care packages

- Data collation tools need to be improved upon to continue reporting disaggregated data for all populations
Thank you for listening

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