



DSD: The View from Recipients of Care

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November 5, 2018

Plan...

- As ITPC, share insights from global engagement with recipients of care on DSD
- Give feedback from CQUIN Pre-Meeting (*Participant*)
- Wrap-up

Different Contexts, Different People, Different Worlds



Who are Recipients of Care?

- People Living with HIV
- Cross-border populations
- Adolescents
- LGBTI people
- People with disabilities
- Sex workers
- People aging with HIV
- Internally displaced people
- Breastfeeding women
- Children
- People using drugs
- Transgender people
- People in prisons and other closed settings
- Heterosexual men
- ...

**In every
conceivable
combination
possible!**

In Every Conceivable Context Possible!



What is the problem that DSD helps to solve?

STRESS TO ROCS



CLIENT PERSPECTIVE



My husband is never going to come for a test at the clinic. He is working all day and it takes us two hours to get to our clinic. What about my previous partner, shouldn't he also have a test?

How can I test the children and husband of this woman living with HIV? They still have not come to the clinic and they live far away. Should I contact her previous partner?



HEALTHCARE WORKER (HCW) PERSPECTIVE

I'd like to have an HIV test, but I don't want to lose my place in the queue to see the doctor. I don't think I'll bother today.

How can I test all these clients in my outpatient department (OPD) for HIV? The queue is so long and I don't have time to provide quality testing. At best, I can test eight people today.



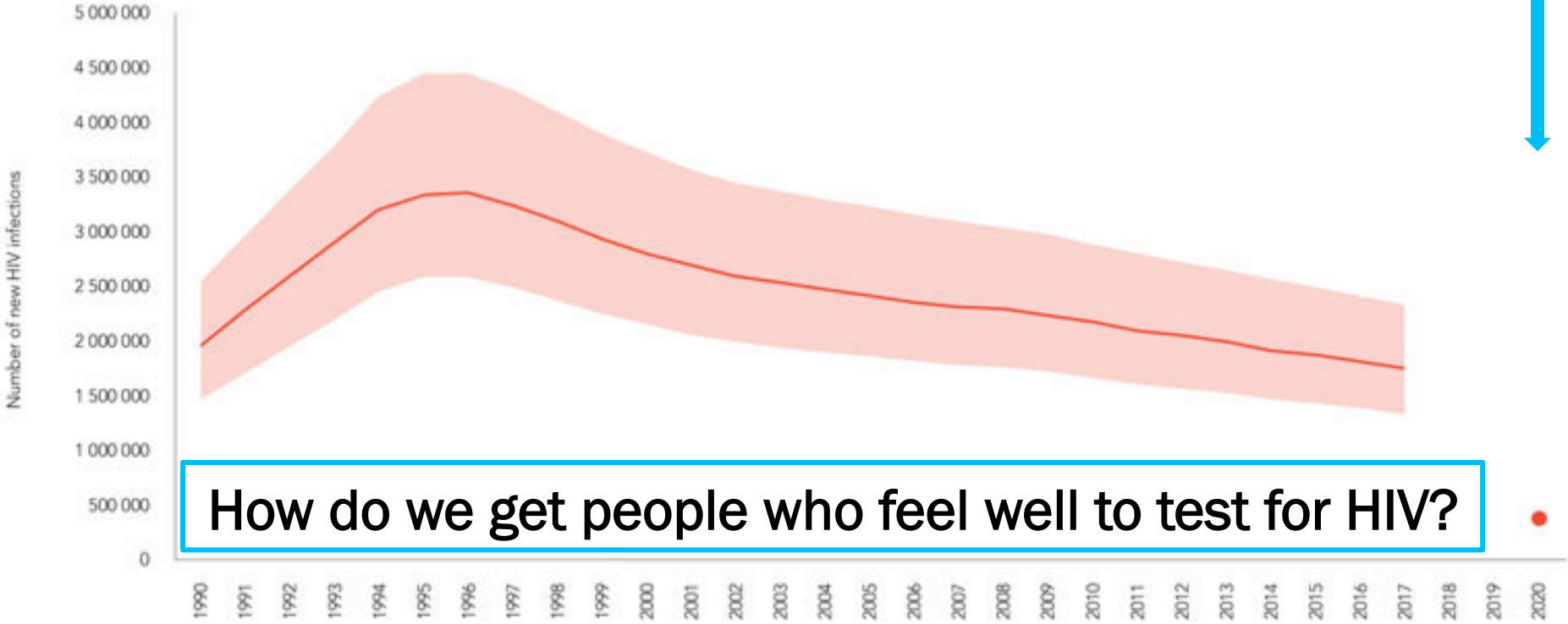
STRESS TO THE SYSTEM



Prevention Crisis

FIGURE 2.3 Insufficient progress on prevention

Number of new HIV infections, global, 1990–2017 and 2020 target



How do we get people who feel well to test for HIV?

— New HIV infections ● Target

Source: UNAIDS 2018 estimates.

What do RoCs Care About the Most?
(when seeking healthcare)

What do **YOU** Care About the Most?

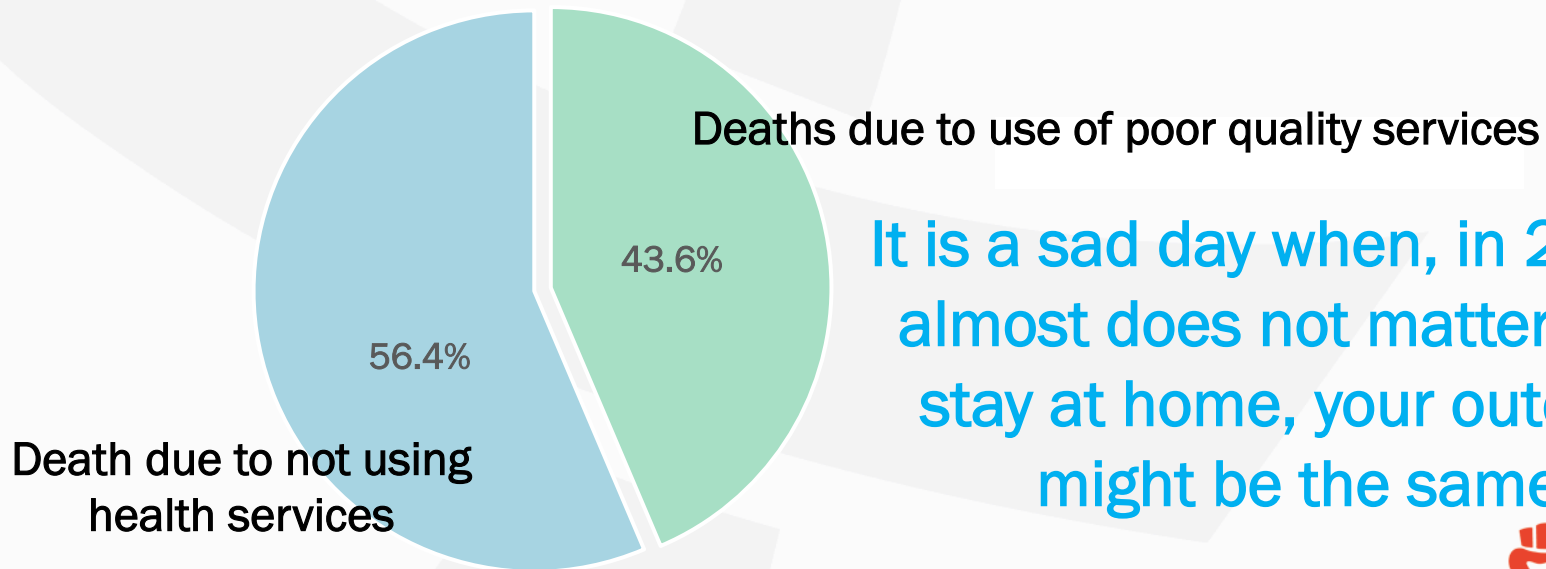
QUALITY

What do Recipients of Care Care About?

A [2018 Lancet study](#) found that of the 812,987 deaths in Western sub-Saharan Africa that were related to health care, 354,744 (43.6%) were due to poor quality of services.

IMPROVED ACCESS NOT AS IMPORTANT AS HIGH QUALITY

Avertable and amenable mortality and mortality related to non-utilization of services versus use of poor-quality services in Western sub-Saharan Africa (Kruk et al., 2018)



It is a sad day when, in 2018, it almost does not matter if you stay at home, your outcome might be the same!

Know What to Do vs Actually Do!

Healthcare providers
don't need more
training, but instead
training must be coupled
with more supportive
supervision and group
problem-solving

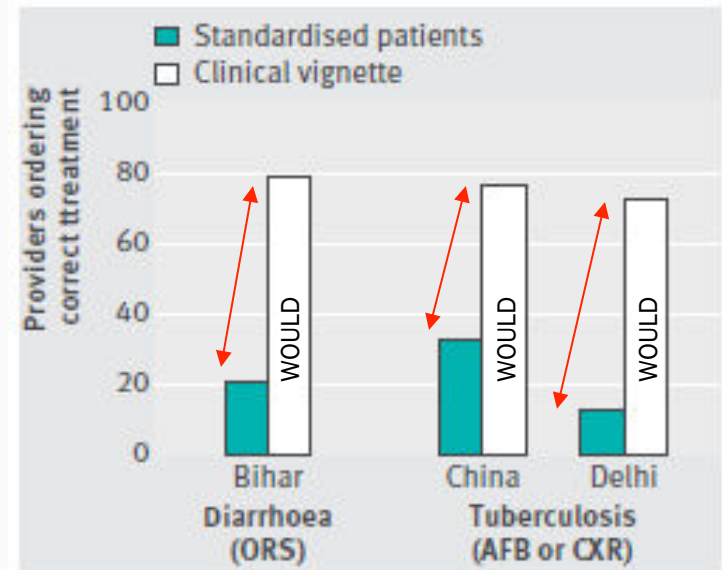


Fig 4 | Differences between how providers said they would manage diarrhoea and tuberculosis in clinical vignettes and what they actually did with standardised patients presenting with the symptoms in the vignettes (ORS=oral replacement solution, AFB=acid fast bacilli test, CXR=chest radiography) ^{13 17 30}

[Lancet](#). 2005 Sep 17-23;366(9490):1026-35. How can we achieve and maintain high-quality performance of health workers in low-resource settings? [Rowe AK](#)¹, [de Savigny D](#), [Lanata CE](#), [Victoria CG](#).

6 Key Insights from RoC around the world on DSD

1. LOW AWARENESS

- Increase **demand**

2. INCOMPLETE KNOWLEDGE

- Increase **treatment literacy**. U=U, resistance.

3. PEOPLE HAVE A DESIRE FOR BETTER SERVICE EVEN **OUTSIDE OF HIV**

- Leverage DSD **beyond HIV** to other chronic diseases for all RoCs to reach Sustainable Development Goal 3 on good health and well-being.

4. FOR ALL

- Attention is required for specific populations. **Appropriate quality care**, reduce frequency of visits.

5. ALONG THE WHOLE CASCADE

- DSD for **prevention** [diff. testing approaches, **well-people incentive** models]

6. ALL CONTEXTS

- Attention is required for **specific settings** [Unstable countries, fragile health systems, dry/rainy season, loss to follow-up]

PRE-MEETING FEEDBACK

Pre-Meeting for Organizations of People Living With HIV

1. Cote d'Ivoire
2. Ethiopia
3. Eswatini
4. Kenya
5. Malawi
6. Mozambique
7. South Africa
8. Zambia
9. Zimbabwe

- Roundtable of **Leaders from People Living with HIV Networks**
- Small survey
- Facilitated discussion on:
 - Survey responses
 - Country experiences
 - Successes
 - Challenges
 - **Key Messages as RoCs**

Key Messages from Pre-Meeting

- **Meaningful Engagement**

- Ensure PLHIV communities are **part of DSD at all levels** (design, planning, policy, guidelines, TWG, monitoring and reporting) and not just during implementation.
- Seat **≠** voice. Some of the **green** scores might be questioned!

- **Demand Creation**

- Let the **demand** for DSD come from **RoCs** and **not from the IPs!**
- IPs are coming with **ready-made models** for pilot. **Target** chasing.
- The best approach is to present a range of options (models) of DSD for discussion, input and adoption by **RoC leadership**.

- **Leverage Learning**

- Pilotitis. CQUIN is an oasis of evidence and learning to be shared for real life implementation. **No need to keep gathering evidence** when neighbouring countries with similar contexts have shown a **model works** - EXCUSES!

Key Messages from Pre-Meeting

- **Community Systems Strengthening (CSS)**
 - Take an approach that **builds the capacity of RoCs** – acknowledge and respect leadership structures and platforms
 - Provide structured support and **accessible funding opportunities**.
- **Build on what is already there**
 - Allow RoCs to give **input in DSD pilots**. This will allow MOHs and IPs to ‘leverage on the lived experience’. Don’t just rename what is already being done!
- **Full disclosure by donors and IPs**
 - At planning stage, so that RoCs are informed and involved in deciding **which DSD model to pilot or scale-up**.
- **Focus on Key populations**
 - Quality of care, stigma, criminalization. Best **reached through their networks** and leadership on the choice and engagement in DSD. Are they engaged enough?

WRAP UP

DSD at Scale Requires

- Robust **MONITORING by COMMUNITIES** to monitor quality and access of services along the HIV cascade
- A more nuanced understanding how to scale/**improve QUALITY** (not just #s)
- Building **COMMUNITY SYSTEMS**
- Truly supporting the shift to **more COMMUNITY-LED & PROVIDED SERVICES**
- **Funding** **COMMUNITY ADVOCACY**

DSD Exposes:

- The **true levers** in and fragility of most health systems
- The crisis of **prevention** and testing
- The need to properly monitor HIV drug **resistance**
- Donor/Gov. **reluctance** to adequately invest in community organizations (prefer IPs)
- The poor job we are doing **reaching key and priority populations**
 - we are fighting, what is often an *ideological battle, with science!*

DSD offers a **neutral entry point** for often highly political discussions and decision-making.

DSD offers an opportunity to **build effective systems and processes** that work for *all* recipients of care.