

Summary Report from the Southeast Asia Stigma Reduction QI Learning Network (QIS+D) 2.0 Redesign Meeting

8-9 September 2023 Novotel Ploenchit Sukhumvit Bangkok, Thailand

Healthqual









UCSF Institute for Global Health Sciences

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# **EXECUTIVE SUMMARY**

#### Day 1: Friday, 8 September

The event commenced with opening remarks by Dr. Bruce Agins (UCSF) and Quinten Lataire (UNAIDS). Dr. Agins framed the work within the lens of equity, which is a key domain of quality, underscoring that stigma prevents successful achievement of equitable health care. In addition, the concept of co-production was introduced as a true equal partnership between providers and users in the design, implementation and evaluation of health services.

The methodology of QIS+D was reviewed, acknowledging the pioneering work of Dr. Laura Nyblade, acknowledging the compiled list of 27 improvement interventions implemented by Network teams.



Following a summary of the progress of QIS+D since its launch in 2017, lightning rounds proceeded, with summaries of QIS+D from each of the participating countries. This framing session concluded with a summary of the QIS+D evaluation (2023), presented by Dan Ikeda via video and a call to implement Treloar's construct of "universal precautions" to reduce stigma.

Resources:

- 1) The Lancet Commission on High Quality Health Systems in the SGD Era.
- 2) Batalden 2023 Coproduction of healthcare services: from concept to implementation. Int J forf Quality in Health Care
- 3) Batalden 2018. Getting more health from healthcare: quality improvement must acknowledge patient coproduction. *BMJ*.
- 4) Nyblade 2021. Stigma reduction: An essential ingredient to ending AIDS by 2030. Lancet HIV.
- 5) Treloar 2022. A universal precautions approach to reducing stigma in healthcare settings: going beyond HIV stigma. *Harm Reduction Journal.*
- 6) Ikeda 2019. A quality improvement approach to the reduction of HIV-related stigma and discrimination in healthcare settings. *BMJ Global Health*.

#### QIS+D Measurement

The results from the pre-meeting survey to gather input about revising Network indicators were summarized, followed by large group discussion. Consensus was reached to include an indicator assessing knowledge about U=U and to routinely capture survey data about key populations as well as HIV. Two specific questions were recommended to address U=U: 1) *Do you agree that people with HIV are free to make their own informed decisions to have condomless sex?* and 2) *True/False: People with undetectable HIV viral load cannot transmit HIV to their sexual partners.* 

Other specific changes were recommended: consolidation of the two measures related to observed behaviors of healthcare workers; moving the supplies and guideline measures to "optional" based on country context; adding an optional measure to ask if providers believed stigma/discrimination were problems in their facility; optional consolidation of the 3 infection transmission related measures; and recommended ongoing discussions about measurement of intersection stigma.

#### Linking QIS+D Data to Clinical Outcomes

The group underscored the importance of capturing clinical disparities as a routine component of QIS+D measurement, utilizing disaggregation of clinical performance data by KP groups and linking results to QIS+D data. Noted implementation challenges included 1) confidentiality and legal protection; 2) stigma from disclosure and MH issues; 3) soft skills for sexual history-taking; and 4) coordination among different sectors of health care. Strategies to move forward were identified including: : 1) SOP development for reporting on disparities; 2) processes for extracting relevant data from existing databases; 3) capturing MH data; 4) establishing protections; 5) HCW training; 6) partnerships with NGOs to enhance reliability of data about KP stigma; 7) partnerships with professional associations; and 8) pre-service education.

There was not sufficient time to effectively explore indicators to assess PrEP stigma. Discussions were facilitated by Dr. Agins and Dr. Todd Pollack (HAIVN).

#### Community-led monitoring (CLM)

Following a virtual presentation from Solange Baptiste (International Treatment Preparedness Coalition), Harry Prabowo (APN+) reviewed implementation of CLM in Southeast Asia, and facilitated group discussion.

All countries expressed strong commitment to CLM and support routine inclusion in QIS+D programs. Concerns were expressed about resource allocation to sustain CLM activities and allow based on national health system and governance. Although data quality is a significant concern, capacity-building initiatives for community organizations are underway. The group noted that a collaborative process between community, providers and policymakers must be advanced to ensure a common understanding of CLM and guarantee its success as a component of national systems to improve the quality of care for PLHIV and key populations.

#### Day 2: Saturday, 9 September

#### The Total Facility Approach

The second day commenced with a recorded presentation from Dr. Laura Nyblade (RTI) on the Total Facility Approach, underscoring the importance of assessing stigma throughout the entire healthcare organization to address stigma in the different areas where PLWH and KPs receive care. Discussion followed about implementation of this approach.

Consensus was reached to strive for a **universal approach to stigma reduction as an integral part of service delivery across all programs and services in healthcare facilities.** To achieve this goal, **routine measurement** is a critical component that will be strengthened by broadening the approach to include multiple diseases and conditions. The group noted that Implementation is complex, requires resources and strategic planning but is vital to ensuring equity in healthcare service delivery.

#### **Knowledge Management**

The importance of a communications strategy in each country was underscored, building on an earlier presentation. Participants were polled and confirmed their interest in multiple approaches to exchanging knowledge and sharing experiences. UNAIDS is considering a variety of strategies to promote communication.

Cedriann Martin (UNAIDS) reviewed the paradigm for knowledge management in global health programs (Johns Hopkins University).



#### Sustainability of QIS+D Programs

The final session focused on sustainability of QIS+D programming in each country, centered around their self-assessments using the Program Sustainability Assessment Tool from Washington University St. Louis. Each country completed this quantitative assessment which provides a framework for further program implementation to assure the ongoing focus of stigma reduction in national quality improvement programs. Results are included below in the Report. Multiple areas require attention if QIS+D programs are to be sutained.

Resource: <a href="http://www.sustaintool.org/psat">www.sustaintool.org/psat</a>

# **FULL REPORT**

# Healthcare Quality Improvement to Encourage Equitable Care: Reducing Stigma in Healthcare Settings

This presentation by Dr. Bruce Agins from UCSF-HEALTHQUAL provided an overview of the QIS+D Network, intended to provide an overview for participants who have not been part of the Network and those who have not attended all of the meetings. The content intends to provide a basic level of knowledge for effective participation in the Redesign Meeting, highlighting the role that **stigma reduction contributes to supporting health equity as a fundamental component of healthcare quality**.

#### Rationale: Why a Quality Improvement Approach is Important for Reducing Stigma in Healthcare

The key points underscoring the importance of routine quality improvement in health facility stigma reduction programs were noted:

- 1. Stigma is a social process requiring systemic action—we need to focus on systems of care, not just individuals.
- 2 The drivers of stigma are common, but their manifestations are often contextual—we need to adapt interventions to context.
- 3. The process of scale up and sustainability are inherently dynamic—we need a structured way to learn as we go.
- 4. HIV programs already support quality improvement—we need to harness existing capacity while layering on new capacity.
- 5. Quality is co-produced—we need to promote partnerships among communities, providers, and governments.

Frameworks and Principles for Implementing the QIS+D Network:

Frameworks and principles that inform the implementation of the QIS+D Network were described:

- 1) WHO Framework for Integrated People-Centered Health Services which unites health services and population health through focus on patient safety, patient-centered care and people-centered health services;
- Lancet Commission on High Quality Health Systems which underscores a framework for system-wide action on quality underscoring that health systems are for people; noting the importance of positive user experience, better health and confidence in the health system;
- the fusion of technical and experiential quality as represented by a Venn diagram by Leonard Berry, where technical care includes the effectiveness and safety domains and experiential quality includes the equitable and people-centered care domains of quality;
- 4) the "4th 90" emphasizing health-related quality of life; (continued on next page)

- 5) the *Institute of Medicine* domains of quality with particular emphasis on equity, defined as "providing care that does not vary in quality because of personal characteristics, such as gender, [sexual orientation], [race], ethnicity, geographic location, socioeconomic status, [and medical condition]," while noting from the *Lancet Commission*, that "quality of care is worst for vulnerable groups, including poor, the less educated, adolescents, **those with stigmatized conditions**, and **those at the edges of health systems**...";
- 6) Stangl's *Health Stigma and Discrimination Framework*, showing that stigma operates at individual, interpersonal, organizational, community and policy levels, ultimately affecting incidence, morbidity, quality of life and social inclusion.

These frameworks underscore the clear conclusion that **stigma and discrimination thwart** access to and the provision of equitable health care.

#### Implementation of QIS+D

Dr. Agins noted the work of Dr. Laura Nyblade (RTI) as seminal to the approach of QIS+D. Nyblade highlights four actionable drivers of HIV-related stigma: fear of transmission, awareness of stigma, attitudes, and institutional environment. These drivers lead to manifestations of stigma that include experienced, anticipated, or perceived stigma, as well as self-stigma. All of these manifestations have negative consequences as they may lead to avoidance of care, refusal to treat, or harassment, which detrimentally affect the processes of care that constitute the HIV prevention and care cascade, including PrEP uptake, HIV testing, diagnosis, linkage to care, engagement in care, and adherence.

The long-term consequences of these stigmatizing behaviors and attitudes ultimately influence the achievement of UNAIDS' 95-95-95 targets, which are crucial for both epidemic control and clinical outcomes in HIV.

#### Network Design

The Multi-country Southeast Asia HIV Stigma Reduction Network was funded with specifications to work at the multi-country level through convening of quality improvement network meetings to include sharing of national data, QI examples and stigma reduction policies with ongoing refinement and evolution of methods to apply QI to stigma reduction. Participating countries apply the QIS+D methodology in their own health systems, overseeing data collection and management, QI training and peer exchange among participating facilities in their national QIS+D networks. These activities were funded by each country, whether through national or donor funds. Facilities participating in the national networks use their QIS+D data to identify areas for improvement, identify potential solutions and test them for adaptation in their clinic environments. Successful interventions are then shared at national level and at the multi-country Network meetings, while national policies and interventions are discussed and shared at the Network level, with ideas then spread for contextual refinement to other countries according to their national policical and health system environments.

#### Measurement Methodology: Uniting data streams to improve outcomes

Traditional methods for measuring quality of care involve review of medical records which do not include specific data related to stigma and discrimination, although aggregated facility

performance data can suggest the presence of disparities in care if indicator data are subsequently disaggregated by key populations. Typically, this is not done routinely. To measure stigma in healthcare settings, QIS+D has adopted a combination of data measurement methods to provide a snapshot of the facility environment related to stigma and discrimination. In addition to disaggregated clinical performance data when available, healthcare worker (HCW) surveys based on Nyblade's *Standardized Brief Questionnaire*<sup>1</sup>, patient experience assessments, health literacy data and, most recently, community-led monitoring (CLM) data. Through the analysis of these combined data sources, a comprehensive snapshot of the quality of service delivery is obtained to inform quality improvement activities and, ultimately, better health outcomes.

# Patient feedback and health literacy Uniting survey and clinical performance data generates a more comprehensive "snapshot" of the guality of service delivery. Clinical performance data Uniting survey and clinical performance data generates a more comprehensive "snapshot" of the guality of service delivery. Clinical performance data Uniting survey and clinical performance data generates a more comprehensive "snapshot" of the guality of service delivery. Healthcare provider survey Uniting survey and clinical performance.

Inherent in this measurement strategy are several limitations, including: 1) disaggregation of facility data by key populations is not common nor is a reliable assessment of sexual orientation; 2) proximate, non-linear measures constituting the "snapshot" require contextual interpretation; 3) lack of familiarity with application of QI methods to survey and qualitative experience data as opposed to clinical data, requiring a "frameshift" for providers; 4) routine meaningful involvement of patients/community in QI activities and co-production are not common but an important stigma-reduction strategy involving putting those affected in the center of the response; 5) understanding experience of patients who do not return to clinic because of stigma and discrimination requires integration of input from the community, particularly for understanding challenges with access and disengagement from care; and 6) engaging leadership to address stigma beyond dedicated HIV programs.

#### Making QI a routine element of stigma reduction programs

Although co-production is a common term in the field of quality improvement, it is not often known in the public health and healthcare delivery program sector. Dr. Agins defined co-production based on the work of Batalden<sup>2</sup>: "Coproduction of health describes the interdependent work of users and professionals who are creating, designing, producing, delivering, assessing, and evaluating the relationships and actions that contribute to the health of individuals and populations. At its core are the interactions of patients and professionals in different roles and degrees of shared work."<sup>2</sup>

To further amplify the concept of co-production, a video was shown: *"The World of Co-Production and QI"*.<sup>3</sup>

#### Conclusions, Future Directions and Closing Thoughts

Through the commitment and participation of its six member countries, QIS+D has shown that routine application of QI to reduce HIV S+D is feasible, that HIV-related stigma and discrimination in healthcare facilities is actionable through organizational and system-level changes, and that data from both patients and healthcare workers can be integrated into routine QI activities. Over 27 strategies have been tested to address the 4 immediately actionable drivers of HIV-related stigma leading to evidence-informed interventions. Activities to assess patient experience and treatment literacy through common indicators have been shown to be important contributors to reducing S+D in healthcare facilities.

To cement stigma reduction activities as part of QI in healthcare facilities and extend throughout the facility, ongoing disaggregation of clinical performance data by key populations is needed but remains an unmet need. Sustainability of stigma reduction activities in healthcare facilities requires integration of QI into national stigma reduction and national QI policies and plans and demands vigilance to continuously address stigma in healthcare settings.

#### Future directions

In 2022, the network conducted an evaluation (Ikeda; see Evaluation section) with network participants which lead to identification of 8 priorities for future activities:

- 1. Intensified emphasis on reduction of stigma related to HIV prevention services, including PrEP and focus on key populations.
- 2. Greater focus on addressing sequelae of structural stigma, including self-stigma, mental health, and substance use.
- 3. Better coordination among funders, NGOs, and governments.
- 4. Promotion of stronger linkages among providers, PWH, KPs, and communities.
- 5. Intensified focus on incorporating patient experience into QIS+D efforts.
- 6. Promotion of U=U messaging among communities and healthcare providers.
- 7. Continued efforts to build QI capacity across all levels
- 8. Continued emphasis on knowledge management to promote rapid exchange of latest research and best practices.

In closing, Dr. Agins noted that the time has come for adopting a "universal precautions" approach to stigma as conceptualized by Treloar, et. al.<sup>4</sup>, uniting the pillars and precepts of equity, healthcare quality and universal precautions through a unifying logic. Through this approach we can propel concerns about stigma to the front of the queue for action by health systems, recognizing that all people may experience stigma and discrimination targeted at one or more aspects of their identities, attributes, practices and health conditions. As we move towards a global implementation of universal health care, quality plays a central role in our ability to achieve success. Can we promote and co-produce equity to reduce stigma through a movement to implement universal precautions to achieve high quality universal health care?

<sup>3</sup>NHS; <u>https://www.youtube.com/watch?v=OpoWdyxAvYo&t=11s</u>

<sup>&</sup>lt;sup>1</sup> "Measuring HIV Stigma and Discrimination Among Health Facility Staff: Standardized Brief Questionnaire." Washington, DC: Futures Group, Health Policy Project. 2013.

<sup>&</sup>lt;sup>2</sup> Batalden P. Getting more health from healthcare: quality improvement must acknowledge patient coproduction. BMJ 2018.

<sup>&</sup>lt;sup>4</sup>Treloar, Cama et al. A universal precautions approach to reducing stigma in health care: getting beyond HIV-specific stigma. Harm Reduction Journal 2022.

# Strategies to scale up and sustain efforts to reduce HIV-related stigma in healthcare settings

This presentation by Dr. Dan Ikeda summarized the evaluation he conducted to identify the enablers and barriers to the scale-up and sustainability of QIS+D.

In-depth interviews for this evaluation were conducted by Dr. Ikeda between November 2022 and March 2023 with stakeholders of the network (n=24), purposively selected to include implementers from all six countries, representing government and community, who had participated consistently in the Network. Data from the interviews were transcribed using qualitative methods and analyzed using implementation science frameworks.

Three primary research questions were developed for interviews:

- 1) What are effective strategies for scaling up stigma-reduction interventions?
- 2) What are effective strategies for *sustaining* stigma-reduction interventions?
- 3) What can the QIS+D do better to make scale up and sustainability a reality?

Several key themes were identified through the interviews:

The importance and challenge of coordination across the health system: All levels of a health system, from Ministries to hospitals, must be engaged to implement QIS+D, as each provides necessary components for successful implementation. The national MOH can be the source of policy change but buy-in from local government is necessary for making changes at the service delivery level. Policy implementation must also be coordinated with departments outside of HIV care.

The importance and challenge of securing and maintaining leadership support: Consistent engagement of leadership at each level of a health system is necessary for both implementation and scale. In particular, scale-up requires expansion of the number of local leaders engaged.

**The benefit of continuous measurement:** Measurement should reflect that S+D reduction is a dynamic practice that intersects with changes in HIV care and institutional realities. Monitoring systems should allow for routine feedback on the efficacy of interventions.

**The need for adaptation:** The success of implementing policy changes at scale is dependent on their adaptation to local contexts. Local Ministries should assume ownership of national guidelines and autonomy on how best to integrate guidelines into service delivery.

**Commitment to engaging communities, but challenges determining "how:"** Feedback loops between beneficiaries (PLHIV, KP) and HCW can strengthen the implementation of S+D reduction. Negative feedback is useful for making improvements, but positive feedback can be a powerful motivator for HCW to continue engaging in the work. Communities should be engaged in decision-making.

Implementation of S+D reduction is a dynamic process that happens in a resource-constrained environment with competing priorities. External disruptions like the COVID-19 pandemic necessitate changes in strategy. Leadership, coordination, and continuous measurement are

key facilitators for sustainable and effective implementation at scale. Notably, support for S+D reduction has grown across health systems in the Network countries. While approaches differ, community engagement is both important in all countries for reaching the populations most affected by S+D and successfully implementing policy changes.

#### Lightning Rounds: Summary of QIS+D 1.0 Implementation: 2017-21

Following a presentation about the QIS+D Network, each country presented in this Lightning Rounds session according to a template that asked for an implementation timeline, summary of cumulative data, program successes and challenges, concluding with their wishes for the next phase of the Network, QIS+D 2.0.

#### Overview for QIS+D: The Southeast Asia HIV Stigma Reduction QI Learning Network

Dr. Bruce Agins on behalf of the QIS+D team (Quinten Lataire, Dan Ikeda, Richard Birchard, Harry Prabowo, Cedriann Martin)

#### <u>Timeline</u>

Dr. Agins began with a historical timeline of the QIS+D initiative. In 2017, the methodology for applying quality improvement methods to reduce stigma in healthcare settings was spearheaded by Bruce Agins and Dan Ikeda through UCSF-HEALTHQUAL, supported through PEPFAR via the Health Resources Services Administration (HRSA). The methodology was introduced at a Design Meeting, in partnership with Dr. Laura Nyblade (RTI) and Dr. Kriengkrai Srithanaviboonchai (RIHES). Measures from Nyblade's healthcare worker survey tool were prioritized during this meeting to form a core set of 8 indicators for cycles of measurement.

Twelve QIS+D Network meetings were convened during which each country presented their program updates. Guest presentations and key topics are described by year:

2018: Implementation plans were presented by country networks. A training program was conducted by the Thai Ministry of Public Health based on their national stigma reduction training curriculum focusing on ending HIV-related stigma in healthcare settings. 2018: At the Network meeting convened in Ho Chi Minh City at Pham Ngoc Thach Hospital, key topics included the introduction of U=U, increased involvement of people living with HIV (PLWH), and the inclusion of patient experience measures in the OIS+D methodology. -2019: UNAIDS Asia-Pacific and APN+ joined the Network as co-conveners, involved with leadership and planning. Patient experience measures were formally launched and clinical literacy measures were introduced. A change package of QI interventions was developed and disseminated. Civil society and subnational delegates were involved in Network meetings. Guest speakers from TREAT Asia and guest speakers from EQHA (FHI360 Cambodia), TREAT Asia stigma research and community scorecards (CDC-US). -2020: Presentations on regional epidemiology (UNAIDS), journey mapping (Dr Jittiman Manonai) There was a focus on journey mapping, a UNICEF-supported panel presenting regional vouth-friendly clinic models and an overview of key populations (KPs) by UNAIDS with guests from Indonesia and Myanmar presenting on stigma challenges in their countries.

Support for QIS+D was transitioned to Gilead Sciences & ViiV Healthcare, as Malaysia and Philippines joined the Network.

-2021: Meetings were conducted virtually during the Covid pandemic. Areas of focus included KP-led service models (IHRI), community-led monitoring (ITPC), a curriculum on self-stigma (Thai MOPH), and mental health among PLWH and KPs (Keuroghlian). -2022: A virtual meeting was held featuring presentations from the TREAT Asia S2D2 project, discussions on integration of mental health services into primary care d presentations on youth-friendly clinics by UNDP and from Chulalongkorn hospital (Wipaporn).

-November 2022 (in-person): Presentations included a universal precautions approach to S+D (Treloar), the methodology for evaluation of QIS+D (Ikeda); community-led monitoring in the Philippines (Rinabor), stigma and transgender health (Samitpol-Tangerine Clinic), peer-led depression screening (Janamnuaysook-IHRI), and issues surrounding PrEP-related stigma (Agins).

-May 2023: Presentations focused on the Total Facility Approach (Nyblade), community-led monitoring panel from Viet Nam, a young key population panel (YKP+), discussions on communication strategies (Martin-UNAIDS) and a comprehensive review stigma among people who use drugs by Trang (HMU) and an S2D2 update.

#### <u>Data</u>

Across the QIS+D Network, over 41 rounds of healthcare worker (HCW) surveys have been conducted, with 55,686 cumulative respondents. Patient experience surveys have been conducted over 26 rounds with a cumulative total of 68,593 respondents, reflecting the commitment of participating countries to understand and improve patient experience, complemented by 20 rounds of clinical literacy assessments with 16,359 cumulative respondents. These data reflect the extensive feedback and involvement of healthcare workers and patients in the quality improvement initiatives of the QIS+D program to reduce HIV stigma in Southeast Asia. The large number of respondents underscores the depth of the program's reach and its commitment to continuous learning and improvement.

#### Successes and Challenges

QIS+D successes have included: 1) **Engagement**: all countries within the QIS+D Network have actively engaged in the initiative, which reflects strong collaboration and commitment; 2) **Application of QI Methods**: QIS+D has successfully demonstrated that quality improvement methods can be applied to reducing stigma in healthcare facilities; 3) **Continuation:** the initiative has secured funding, which is necessary for its continuation and expansion of its activities.

Challenges for QIS+D include: 1) **Sustainability**: maintaining the momentum and activities of the QIS+D initiative remains a challenge, particularly as donor funding diminishes for some national programs; 2) **Expansion**: engagement of other countries to join the network has proven difficult, indicating a need for different approaches or demonstration of the program's value; 3) **Documentation**: improvement in the documentation of the quality improvement work being implemented is needed to understand and disseminate best practices; 4) **Personnel turnover**: in some countries, Ministry and facility turnover has affected continuity and institutional memory;

and 5) **Funding**: despite renewal of funding, overall resources are small and potentially limit the scope and scale of activities.

#### Network Wishes from HEALTHQUAL:

<u>Universal Precautions for Stigma Reduction</u>: adoption of a policy supporting a universal precautions approach to stigma reduction across all member countries.
 <u>Integration into National Policies</u>: Integration of QI and specifically QIS+D activities into the national quality policies and strategies and national stigma plans of the countries where this has not yet happened, is a critical strategy to ensure that the work of the QIS+D Network is embedded within the larger healthcare system to maintain focus on stigma reduction in the healthcare sector.

These points reflect the ongoing journey of the network, highlighting both its achievements and the obstacles it faces. As the network looks to the future, it aims to solidify its practices, expand its reach, and integrate its activities into broader national health agendas.

#### VIET NAM

#### Viet Nam S+D Program Highlights

Presented by Dr Do Huu Thuy, Viet Nam Authority of AIDS (VAAC), Ministry of Health (MOH)

#### <u>Timeline</u>

Starting as a pilot, the program has expanded to cover 6 high HIV burden provinces with support from CDC/PEPFAR, HAIVN, and UNAIDS. In 2018, the QIS+D program was implemented in three provinces, bolstered by the *Ministry of Health Directive 10* for stigma and discrimination (S+D) reduction. By 2020, two additional provinces were included, and VAAC introduced KP-friendly criteria for healthcare facilities. The program reached 6 provinces by 2021.

#### <u>Data</u>

Despite disruptions caused by COVID-19 and healthcare restructuring, Viet Nam completed 7 rounds of data collection and is currently in the 8th round. Healthcare worker (HCW) surveys included 27 sites with 4,064 respondents; patient experience surveys covered 7 rounds, 30 sites, and 7,716 respondents; clinical literacy matched these figures.

#### Successes and Challenges

**Key Successes** have included: 1) **improved health provider attitudes**: documented improvement in health providers' attitudes and knowledge regarding HIV and stigma and fear of transmission have been demonstrated; 2) **improved client experience**: noted advancement in viral load literacy and understanding of U=U have occurred; 4) **data use**: data are used to identify gaps and reinforce policies to protect people living with HIV (PLWH) and key populations (KPs); 5) **community engagement**: the community advisory board (CAB) model has been endorsed by the Government of Viet Nam (GVN), accompanied by peer support programs to enhance client feedback, experience sharing discussions and co-design to create KP-friendly services. **Policy successes** have included: S+D monitoring through implementation in HIV service sites supported through the national HIV strategy; introduction of KP-friendly standards of care, national CAB policy guidance; dissemination of U=U messaging nationally; a gender-affirming policy statement on homosexuality; and the introduction of PrEPQUAL to address stigma targeting pre-exposure prophylaxis (PrEP).

**Challenges** include: 1) **understanding stigma**: gaps remain in understanding of PrEP and KPrelated stigma at the community level; 2) **bureaucratic delays**: cumbersome donor-funded activities' approval processes slow progress; 3) **HCW turnover**: turnover rates are high, attributed to a broader 'brain drain' and burnout in the post-COVID period; 4) **resource commitment**: local commitment and resources are needed to expand and sustain QIS+D; 5) **institutionalization**: challenges remain in terms of how to sustain the program amidst shifting global priorities.

#### Network Wish:

1. <u>Indicator revisions</u> to address current program needs and better reflect the landscape.

2. <u>Experience Sharing</u>: Further sharing of models, tools, and success stories for the QIS+D program.

3. <u>Stigma Focus</u>: A greater focus on internalized, intersectional, and PrEP-related stigma, as well as stigma in non-HIV settings.

4. <u>Rotating Meetings</u>: To organize meetings in various countries for better collaboration.

Viet Nam's achievements in the S+D program illustrate effective community engagement, use of data to guide policy, and successful expansion and adaptation of the program despite challenges. The program has made significant strides in reducing stigma and improving the experience and health outcomes for people living with HIV.

Viet Nam has successfully translated program success into policy change, demonstrating commitment at the governmental level to institutionalize improvements and address stigma-related issues. Priorities include strategies to ensure nationwide policy implementation. The presentation indicates a strong desire to evolve the program by refining indicators and addressing different forms of stigma in varied environments. The hope is that this network meeting will help guide the program toward these goals.

#### LAO PDR

#### S+D Routine Monitoring in Lao PDR (2018-2022)

Presenter: Dr. Khanthanouvieng Sayabounthavong, Senior Technical Advisor, Center for HIV/AIDS & STI, Ministry of Health, Lao PDR.

Timeline:

Over the course of five years (2018-2022), Lao PDR implemented eight rounds of routine QIS+D monitoring related to HIV services. The data collection methods evolved from using REDCap to paper forms (4<sup>th</sup> and 5<sup>th</sup> rounds) and finally to Google Sheets.

<u>Data</u>

A total of 9,317 healthcare workers were surveyed over eight rounds. Patient experience, along with clinical literacy, was assessed in six rounds, with 3,312 and 3,335 responses respectively. Data were collected from 11 ART (Antiretroviral Therapy) sites with two community-based Point of Care (POC) facilities added in the eighth round. Additionally, six new POC sites will be included in the next round of monitoring. Observed improvement was noted in performance over the first five rounds, however, a decline was noted during the COVID-19 pandemic, likely caused by enhanced fears of coronavirus transmission. Improvement has again been shown in the most recent round of data collection.

#### Successes and Challenges:

**Successes** have included: 1) **innovative approaches** in the country's S+D reduction programs which are underscored by the positive trends in the data; 2) **sharing of data** with international organizations and partners; 3) **alignment with the MOH quality policy** and strategy, particularly the "5 good 1 satisfaction" strategy aimed at improving equitable access to quality health services for the Lao population.

**Challenges** include: 1) **integration of plans and projects** across different sectors and with various donors; 2) **advocacy for the acceptance of QIS+D as a part of national health service delivery** in all relevant service areas and at all health sector levels.

Lao PDR's efforts in monitoring and addressing S+D within HIV/AIDS services showcase a commitment to improving healthcare outcomes. The ongoing adjustments to data collection methods and the expansion to new POC sites indicate a responsive and evolving program. Despite setbacks during the pandemic, the resumption of effectiveness of the program and positive trends in the health system.

#### MALAYSIA

#### Stigma Discrimination Reduction Initiative in Malaysia

Presenter: Dr. Samsiah Awang, Head, Centre for Healthcare Quality Research Institute for Health Systems Research, Ministry of Health on behalf of the Malaysia team including Dr Anita Suleiman, Dr Samsiah Awang and Dr Izzatur Rahmi Mohd Ujang

Malaysia has embarked on a significant initiative to reduce stigma and discrimination (S+D) associated with HIV, utilizing the Quality Improvement (QI) method. This program is a collaborative effort spearheaded by the Disease Control HIV sector, led by the AIDS officer, with capacity building overseen by the Institute for Health Systems Research (IHSR). The Malaysia AIDS Council facilitates the partnership between governmental and non-governmental organizations.

#### <u>Timeline</u>

Implementation has occurred in two phases, with phase 1 initiated in 2020 involving 10 facilities. Activities included understanding the QA/QI approach, finalizing the project indicators and data collection tools. A baseline survey was conducted, followed by strategy designing, continuous coaching, and subsequent re-evaluations in 2021, 2022, and 2023. A scale-up phase was launched in 2022 involving expansion to 55 sites across all states, and implementation of similar approaches as in Phase 1, with additional baseline surveys.

Other activities have included the introduction of enhanced QI training that has culminated in a compendium of best practices, improved workshops, and champion sharing sessions.

#### <u>Data</u>

Four rounds of HCW surveys were conducted over 4 rounds at 10 sites involving 9,066 cumulative respondents. In Phase 2, 11,051 HCWs responded over 2 rounds at 55 sites with 11,051 cumulative respondents. Patient experience surveys including clinical literacy questions were completed over 4 rounds at 10 sites with 2,439 cumulative respondents, and in Phase 2 over 2 rounds at 55 sites with 2,621 cumulative respondents. Notably,

across all domains and phases, there has been a noted improvement in stigma and discrimination outcomes, with fewer individuals reporting negative experiences.

#### Successes and Challenges

The QIS+D Program has made significant strides in Malaysia, expanding and refining its approach to reducing S+D in HIV care with notable **successes** including: 1) **scale-up**: the program expanded from 10 sites in Phase 1 to 55 in Phase 2, marking substantial growth and increased reach; 2) **knowledge sharing**: a *Compendium of Best Practices* was published, detailing effective interventions from Phase 1, serving as a resource for ongoing and future efforts; 3) **capacity-building:** over 200 staff members received training in Quality Improvement (QI) techniques, bolstering the program's expertise.

**Challenges** include: 1) **respondent fatigue** demonstrated by a reducing trend of respondents among HCWs and PLHIV across QI cycles, partly attributed to survey fatigue and the repetitive nature of the questions; 2) **community engagement** is crucial and needs to be expanded; 3) **response validity** has been raised through concerns about false 'positive' responses from PHLIV due to fear of being ostracized by HCWs; and 4) **sustainability of QIS+D** as the project faces challenges in maintaining momentum amidst staff turnover, ensuring buy-in from new leadership, and integrating various disciplines like dental services.

Significant highlights from the first re-evaluation of the project in 2023 include:

- The initiative emphasizes a structured, quality-driven approach to mitigating the impacts of S+D in healthcare related to HIV.
- Capacity building and continuous learning are integral, with the establishment of best practices and sharing of successful strategies among champions in the field.
- Regular re-evaluations ensure ongoing monitoring and assessment of the initiative's effectiveness.

#### Way Forward and Strategic Goals:

In the next cycle, emphasis will be placed on ensuring sustainability and measuring S+D as a national quality indicator. Strategies are being developed to maintain momentum and to integrate S+D reduction into the fabric of the national health system.

#### Network Wish

The major wish for the next cycle is to focus on strategies for sustainability and learning by applying frameworks for adapting best practices/evidence-based interventions to new contexts.

The Malaysia QIS+D program reflects a strong commitment to addressing S+D in health care with a shared learning approach through a proactive and structured effort in combating S+D, with a clear direction for future improvements and the fortification of its HIV care strategies. The partnership model and the phased approach have set the stage for for a scalable and sustainable program with potential for substantial impact on healthcare quality and patient experiences. Vigilance will be needed to foster adaptive strategies and engagement methods to maintain program integrity and sustainability.

#### PHILIPPINES

#### **Philippines QIS+D Overview**

Presented by Ildebrando Ruaya, Jr., Quality Improvement Specialist, SHIP

The Philippines QIS+D program was established and currently operates as a PEPFAR supported Quality Improvement Learning Network through UCSF-HEALTHQUAL that is led and managed in country by the Sustained Health Initiatives of the Philippines (SHIP).

#### <u>Timeline</u>

The Philippines S+D QI Learning Network was established in 2020 with a focused effort to address stigma and discrimination in healthcare. Baseline surveys were conducted in 2021 to establish benchmarks and followed with another round in early 2022. A third round is currently underway that also includes the clinical literacy questions.

#### <u>Data</u>

HCW surveys conducted over 2 rounds and 6 sites have included 654 respondents. The Patient Experience survey has been conducted with 105 respondents across the surveys. To date, convenience sampling has been used, however in subsequent rounds a sampling approach will be implemented to assure targeting of areas most frequently used by PLWH.

Data systems are under continuous development and refinement, demonstrating an improvement approach to achieving high quality data.

#### Successes and Challenges

Successes in the young Philippines program have included engagement of clinics in QI mentoring to build capacity for improving HIV services; de-identification of registration forms to protect confidentiality; the evolution of client feedback forms to focus broadly on quality of services beyond specific assessment of stigma and discrimination; and the growth of a platform for peer exchange through the QILN.

**Challenges** have been recognized including a **lack of standardization of HIV service delivery**, **resistance to QI mentoring and support** for capacity-building of quality management programs among some programs, and the **documentation of improvement work**. Of note, the activities have identified a **need for governmental policies** to address stigma and discrimination, **engagement of the Department of Health** to devote resources to address stigma in the healthcare system, and participation of the **private health sector**. Network Wish:

The wish for the Philippines is to extend the linkage of QIS+D to improve results along the treatment cascade with particular focus on young key populations and broad promotion of health equity.

#### THAILAND

#### **QIS+D** Overview

Presented by Darinda Rosa, M.D., Division of AIDs and STIs, Department of Disease Control, Ministry of Health

Following pilot activities in 2017 before the formal launch of QIS+D, Thailand began strategic expansion and refinement of its existing S+D curriculum.

#### <u>Timeline</u>

In 2017, the program expanded to include 48 hospitals in 16 provinces, while optimizing the S+D curriculum for broader reach and impact. QI trainings were conducted for participating sites, led by consultants from the Thai HA Program. As the program evolved, QI projects were initiated at several hospitals and were spread by provincial governments, most notably in Songkhla.

Although the pandemic delayed the planned scale-up to 70 provinces and 115 hospitals, the national program continued to implement its national 3x4 program. Innovative initiatives were begun during this period, including a crisis response system (CRS) and the Self-Stigma Reduction Program (SRP), signaling a multi-faceted approach to tackling both externalized and internalized stigma in the healthcare setting. Thailand also established e-learning programs to reach students in the health professions.

Since 2022, the national scale-up reached 71 provinces and 151 hospitals, integrating SRP in 16 provinces and 20 hospitals, and CRS in these provinces plus Bangkok.

#### Successes and Challenges

**Successes include** 1) **effective networking** with the MOPH, private sector, NGOs, GFATM, and the PLWH community; 2) **integration of CQI into the national 3x4 stigma reduction program;** and 3) **ongoing monitoring and evaluation.** 

**Challenges** and **future goals** include: 1) **expansion of the SD CQI package** to achieve nationwide coverage, aiming to reach 80% of clinical facilities by 2026; 2) **ensuring the integration of S+D-continuous quality improvement (CQI) into routine work; 3) strengthening community linkages** with community service organizations, PLHIV, and key populations; and 4) **creating public awareness through strategic campaigns** and new perceptions to combat HIV-related stigma and discrimination.

#### Network wish

Thailand would like to incorporate community-led monitoring into the national S+D program frameworks, and to expand opportunities for international exchange and learning with other countries.

#### Cambodia QIS+D Overview

Presented by Dr. Ouk Vichea, Director of NCHADS (National Center for HIV/AIDS, Dermatology, and STD), Ministry of Health

#### <u>Timeline</u>

NCHADS, along with partners such as EpiC/FH360 and CRS, has expanded the implementation of its method for conducting S+D surveys among both healthcare workers and patients, the Patient Satisfaction Feedback (PSF), from 4 provinces in 2017 to all 25 provinces by Q3 2023. CQI for HIV care and SOPs for patient satisfaction and Key Population Friendly Services have been developed and disseminated. More than 130 healthcare providers received training on these new SOPs in 2022.

#### <u>Data</u>

HCW and patient experience surveys have been conducted across 72 sites, revealing concerns from HCW about blood drawing from PLHIV and a notable percentage of HCWs wearing double gloves. Patients reported a high satisfaction rate (83-88%) with the quality of their care.

#### Successes and Challenges

Successes include 1) PSF coverage at all ART sites, with demonstrated high satisfaction rates; 2) raised awareness and an increase in PSF data use for quality improvement; and 3) recognition by patients about the importance of their feedback, leading to increased respondents to the PSF surveys.

**Challenges** include 1) a **decrease in HCW participation in PSF** during 2023; 2) continued reluctance to **PSF data for QI** at some sites; 3) **increased workload for survey administration** without additional resources.

#### Network Wish

Cambodia would like to see an updated and precise PSF questionnaire for patients and providers, tools to optimize the use of PSF data for QI, and guides for community networks to maximize use of PSF and clinical literacy measures, as well as CLM data.

Wishes for growth of QIS+D in the Cambodian health system include continuation of effective HIV policies and resources amidst decreasing external funding, policy changes to cover HIV services through the Health Equity Fund and assurance of access to services for all PLHIV and KPs. An important wish is to see the alignment of the PSF and CLM programs with the Ministry of Health's national quality improvement program.

#### **QIS+D INDICATORS: Review and discussion**

The responses from the pre-meeting survey to revise the QIS+D indicators were reviewed, followed by a lengthy discussion about the measures. Comments from the participants reflected different perspectives based on country, role and experience with the current set of measures. Although results were not uniform, consensus was reached on several issues which are summarized below. Given the length of time needed to review the HCW worker measures, the patient experience measures were not reviewed and will be considered through a separate conversation in the coming months.

#### Consensus was reached on the following issues:

1. Countries that are not currently measuring HCW stigma focusing on **key populations** should begin and will be asked to report findings at future QIS+D meetings.

2. The **two measures on observed behaviors of HCWs can be consolidated**. Results for both indicators have been similar and are consistent with increasing and decreasing trends. The consolidated question would read:

"Have you observed HCW colleagues providing poorer quality of care to a PLWH or be unwilling to care for a PLWH in your facility"?

3. Discussion focused on relating measures to the key drivers of stigma in Nyblade's model. For countries that wish to add an indicator on awareness, it would read something similar to this:

#### Do you believe that stigma or discrimination are a problem in your healthcare facility?

If this measure is adopted, it would need to be actionable, and benefit from additional information about which parts of a facility are of concern.

4. Although there were different opinions about each of the 3 measures on infection transmission, the group gravitated towards keeping all 3 measures related to contact with PLWH, although countries may wish to keep only one or two measures. The three questions include: a) contact avoidance; b) double-gloving; and c) avoid drawing blood.

We agreed to use the word "routinely" instead of "typically" in the question about wearing double gloves when providing care to PLWH and to insert the word "only". The new question would be phrased as:

#### Do you wear double gloves routinely when providing care to PLWH and not to other patients?

5. We agreed to make the question about **supplies** optional. Some countries do not include it.

6. Although consensus was not reached about the question asking about **guidelines**, countries may wish to keep or remove it. If kept, the need for specifying whether there are *facility-specific guidelines* was raised as an important modification. The group was more concerned about

whether the guidelines were being implemented, although measurement in the QIS+D data sets would be difficult. This measure will be considered **optional** and will not be considered part of the QIS+D core set.

7. The group unanimously agreed to adopt a **new measure addressing U=U**. The following questions were developed:

a) Do you agree that people with HIV are free to make their own informed decisions to have condomless sex?

b) True/False: People with undetectable HIV viral load cannot transmit HIV to their sexual partners.

We decided that these two questions were not the same although we can also track them to see if they produce similar results. We considered wording about whether the provider communicates zero risk of transmission if a person has undetectable VL, however, many respondents in the facility would not be typically communicating with patients directly about this topic in the scope of their facility responsibilities.

Understanding of U=U will be considered in the review of patient experience measures and some countries are measuring this already as part of health literacy questions.

8. The group has consistently emphasized the importance of assessing **intersectional stigma** in our data, however direct measurement of intersectional stigma remains challenging. Through adoption of measures about S+D towards different KPs, we will get a picture of intersectional stigma. We will hope to pursue discussions about intersectional stigma in subsequent meetings.

#### LINKING STIGMA AND DISCRIMINATION TO CLINICAL OUTCOMES

Participants were asked to discuss in small groups how they can link data that measures stigma and discrimination in health facilities to clinical outcomes. Often this question is posed by policymakers and donors, and represents an area that is not addressed directly in medical contexts. Formal links from QIS+D data to clinical outcomes are not well-developed and require consideration.

Participants were asked to discuss the following questions in their country teams and report back to the group.

1. Is it important to show that there are disparities in care that result from stigma and discrimination?

2. How can data about disparities be used to drive changes in policy and program?

3. What are the barriers to capturing data about different populations beyond age and sex groups? (e.g., key populations, mental health)

4. What steps would be needed to overcome these barriers?

#### 5. Should we make collection of these data routine as a part of the QIS+D Network?

Attendees reached consensus about the importance of using clinical data to show whether disparities exist in clinical outcomes, and that clinical disparities and key population data are important to capture as part of QIS+D work. Through disaggregation of performance data, results can be linked with other stigma indicators.

Implementation, however, will include challenges which were common across the countries. These challenges include: 1) the legal environment and data confidentiality; 2) stigma of revealing KP identities and mental health conditions; 3) "soft skills" to elicit these data from patients, particularly related to sexual orientation and drug use; and 4) coordination among different sectors of care and treatment.

This last point involves different units within Ministries of Health in some countries to link stigma and treatment data, involving ownership of databases and processes for stimulating data use. Concerns about overload of indicators on providers were also noted.

Despite these barriers, country teams identified action steps and a way forward which are described in the reports from the small groups. Some common strategies include development of SOPs for routine assessment of disparities, processes for extracting data on affected groups from existing data systems, capturing data about mental health, addressing issues of disclosure and assuring privacy, developing trainings for healthcare workers on stigma and disparities, strong partnerships with NGOs and ensure routine, reliable assessment of KP stigma.

One important strategy that is often not explored relates to partnerships with medical and nursing associations and other academic partners, especially to advocate for education to build capacity to discuss sexual orientation, sexual health and behavioral health with patients. Including these elements in pre-service education as a component of stigma reduction remains an unmet need, although Thailand is now developing a pre-service module on stigma.

Specific country feedback is summarized below:

#### Viet Nam

1. Showing disparities is very necessary. The only way to know if a gap exists is to measure, particularly with respect to KPs.

2. Data on disparities can drive policy changes and planning at all levels. At the community level, data can be used for advocacy and to support resource allocation. At the program, data can be used for improvement and change. At the national, province and commune levels, the aggregated data from facility reviews is packaged for policymakers to guide policy.

3. Barriers to measuring disparities include the fear of data being used for harm and reinforcing providers' stigmatizing attitudes, notably towards people who use drugs (PWUD). Careful attention to who collects and can access data will be important to avoid misuse.

4. To overcome barriers, regulations, guidelines and SOPs will be helpful, especially protections for KPs. Training will be needed, as well as linking data with other kinds of information being collected.
5. Next steps include establishment of the regulatory framework, as well as a monitoring

framework. These frameworks will be needed to support implementation. Dissemination and training on these frameworks will be needed. Routine data collection to drive improvement, and

promotion of literacy for KPs are both needed in the next series of action steps. Advocacy for human and financial resources, technical support and political will all be important to ensure success.

#### <u>Malaysia</u>

1. Stigma results in disparities that are important to measure, including reduced access to care. The impact is felt on both treatment and prevention given that treatment=prevention.

2. Data about disparities, particularly beyond just age and sex, will allow targeting of interventions and formulation of strategies. Creating awareness programs for different groups, including the general population, community leaders, healthcare providers and political leaders is necessary, involving different interventions. Policy changes are important to support these interventions and strategies, especially from the Ministry of Health.

3. Culture and religious beliefs are important barriers that need to be addressed. Overcoming discomfort of providers to discuss sex is a priority, with equal emphasis on privacy and confidentiality of data. This will require building skills and confidence among healthcare providers to talk about key population related issues, especially sexual activities.

4. A key strategy is the partnerships with NGOs so that in healthcare settings community works hand in hand with providers which is a powerful tool to overcome stigma. At the policy level, community members participate in budgeting meetings with policymakers. Regarding data, digitalization ensures privacy and prevents physical viewing of data, which are managed by the NGO. One-stop care settings and institutionalization of programs will facilitate change. To address resource limitations, teams should be designated to address these multiple issues.

5. Continuous data monitoring emphasizing equity for KPs in healthcare is an important element to include in ongoing S+D programs. The interval for data collection can be extended to reduce burden while not sacrificing quality, drawing a distinction between monitoring and improvement.

#### Lao PDR/Philippines

1. Showing disparities is an important element of measuring the quality of care. Measurement of stigma is complex given the intersectionality of stigma. Geographic and socioeconomic factors may contribute to stigma.

2. Data should identify the problems and point to solutions. Data are especially needed, and have been used to develop KP-focused interventions.

3. Legal barriers exist, and especially pose difficulties for people to admit to drug use in the Philippines. Transgender is not considered a legal identity in Philippines preventing its inclusion as a gender category. Reluctance to admit mental health issues may also exist, although variation may be present across countries. On the provider side, knowledge about mental health is limited among HIV providers in some countries. Access to referrals is also important to consider when assessing for mental health, especially with respect to availability outside of normal working hours.
4. Strategies to overcome barriers include creative solutions to work around governmental barriers, such as partnering with academic institutions which are not subject to government restrictions. Advocacy for reform from all constituents is needed along with capacity building for other HCWs to care for PLWH and KPs as integrated care evolves. Protection of information entered into surveys will facilitate participation.

5. Disparities should be a part of the QIS+D work but frequency needs to be addressed.

#### **Thailand**

1. Measuring disparities should occur routinely and is a priority.

2. Current data systems should be used to capture disparities in care but need to be adapted to measure access.

3. An important barrier is the absence of mental health data. The burden of multiple indicators, surveys and databases was noted, with a goal to integrate QI assessments.

4. One potential strategy is to add stigma as a core element of the Disease Specific Certification (center of excellence) programs which will also facilitate alignment of various quality programs.

#### **Cambodia**

1. Disparity in care is most important to SD and for QI.

2. Data on disparities can be used as strong evidence to improve the system of the clinic and be used to provide guidance on program design and policy. The goal would be to set regional standards, and guidance for accreditation and licensing.

3. One potential barrier to measuring disparities is willingness to disclose KP and HIV status. Disclosure is of less concern in facilities where people regularly seek care, but difficult for walk-in patients. Identification and recording of mental health issues continues to be a gap requiring skills development and documentation.

4. Three key strategies were identified: 1) acknowledge and address KP S+D; 2) development of SOPs and curricula for healthcare workers; and 3) routine data collection on S+D.

5. Make data collection on disparities routine, which is especially important to address intersectional stigma.

#### **Community-led Monitoring**

Moderated by Harry Prabowo, APN+

# The Role of Communities in Measuring and Mitigating Against HIV-Related Stigma: Citizen Science

Presented by Solange Baptiste, Executive Director, International Treatment Preparedness Coalition

Citizen Science is an initiative of ITPC that represents the demand side of quality improvement. It moves from models of 'data extraction' to 'data democracy', by combining community-led interventions including CLM, implementation science, and a novel methodology called Life Mapping, which uses collaborative and participatory visual media tools to effect advocacy. The process empowers participants and respects their expertise.

CLM is a process through which communities lead routine monitoring; create indicators to routinely track those priorities; collect data; analyze the results; and share insights from the data with a larger group of stakeholders. Communities then work alongside policymakers to co-create solutions to appropriately design and target interventions, especially focusing on stigma.

Key challenges include longer than anticipated lag times for orientation and implementation; balancing community-defined indicators with those required by donors; suboptimal data use,



ITPC Community-Led Monitoring Model 2021

data ownership and security under CLM and harmonization of national and global indicators.

Regional Community Treatment Observatories West Africa (RCTO-WA) was a 3-year Global Fund regional project on CLM and included 11 countries and 101 health facilities. CTOs collect and analyze data on availability, accessibility, acceptability, affordability and appropriateness of HIV care and services. Sub-analyses of RCTO-WA qualitative data showed that key populations have different reasons for not accessing ART than the general population. For young people, issues of confidentiality and privacy emerged as a top reason for not accessing ART, whereas for MSM, SWs, and PWID, fear of S+D was the key reason. Further findings and analyses can be found here: *Data for a Difference* and *They Keep Us on Our Toes* 

Results from the IPTC Global Treatment Access Survey reported that 64.6% of respondents experienced an instance of anticipated stigma in the previous 12 months, and 37.8% of respondents experienced an act of stigma in the previous year, including gossip and harassment. Members of KPs were especially vulnerable to stigma from HCWs and were twice as likely to be denied services.

Community pandemic preparedness activities included CLM of COVID-19's effects on service delivery and lived experiences of PLWH in China, Guatemala, India, Nepal, and Sierra Leone.

In her concluding remarks, Baptiste emphasized that for CLM to be successful, strong leadership is needed and the model must be embedded in the national response.

ITPC resources (i.e., videos, fact sheets, reports) can be found at itpcglobal.org

#### **Community-led Monitoring in the Asia-Pacific**

Presented by Harry Prabowo from APN+

This presentation focuses on community-led monitoring (CLM) activities in the Asia-Pacific region. CLM is emerging as an invaluable mechanism for collaboration between affected communities, providers and Ministries of Health that has the potential to address significant and practical challenges in HIV service delivery. Documented instances illustrate its role in initiating joint problem-solving and policy adjustments. The current regional landscape includes CLM as a donor and technical partner priority that faces many implementation challenges as funding has supported diverse monitoring tools and distinct capacity-building initiatives. This variation underscores the need for consistency, communication and clarity of the principles and objectives of CLM.

Community leadership and engagement in CLM is contingent on a number of factors, including the capacity and skills of community-led organizations, the availability of funds and the commitment of partners. Despite availability of resources for CLM projects through international funding, long-term funding, leading to concerns about the sustainability of CLM. Moreover, national leaders are hesitant to link CLM data to national information systems to guide programme improvements and decision-making.

Priority focus areas for CLM have been identified in three major domains:

-Maximizing Equitable Access: ensuring everyone has equitable access to HIV services and solutions, promoting combination HIV prevention, achieving the 95-95-95 targets for HIV testing and treatment, ending pediatric AIDS and eliminating vertical transmission.

-Breaking Down Barriers: gender equality, empowerment of women and girls, supporting community leadership, and upholding human rights to eliminate stigma and discrimination.

-Resourcing HIV Responses: advocating for universal health coverage, service integration, and securing investments and resources for sustained and efficient HIV responses.

The Seven Alliance recently sponsored a CLM mapping exercise with eight countries with several objectives: 1) to identify ongoing CLM projects and understand their progress, challenges, and gaps; 2) to provide an overview of the development stages of CLM systems and the level of engagement by national networks of key populations (KP) and people living with HIV (PLHIV); 3) to identify needs for capacity building and technical assistance; and 4) to gather insights from regional KP/PLHIV networks about their contributions to CLM.

Notable enabling factors for CLM include initial government buy-in, funding from international donors, UNAIDS support, and collaborations among community organizations, governments, TA providers, and donors. Successful practices were noted from Nepal, Cambodia and the Philippines. The involvement in National and District level CLM Task Teams in Nepal has sets a positive precedent. Both Cambodia and the Philippines have integrated CLM into their national AIDS Strategic Plans.

Identified barriers to CLM include a lack of collective understanding, limited organizational capacity and the uncertainty of long-term funding.

Recommendations from the workshop include **capacity building** through: 1) strengthening the expertise of community-led organizations to implement CLM and promote cross-country learning; 2) capacity-building to promote community leadership of CLM; 3) advocacy for ongoing funding and integration of CLM into national plans; and 4) establishing a community of practice and information repository on CLM; **a unified CLM system** through establishing and implementing a **unified CLM system** in each country with a CLM dashboard of CLM indicators; **strengthened tools** 

**and data systems;** and **targeting sustainability** through integrating CLM into national HIV responses and mobilization of resources for ongoing support.

#### **CLM Small Group Discussion**

The following questions were posed for discussion:

1. Is your country currently implementing a CLM program by the community?

2. Which one is more feasible (based on your country's context): CLM be integrated into QI activities or QI integrated into CLM?

3. Should CLM be considered a separate component of QIS+D given locations of implementation?

4. What will be the action plan for the integration between QIS+D and CLM

5. Please list out possible/potential resource to integration between QISD and CLM

<u>Current Implementation:</u> Each country is implementing CLM at some level, some as part of national programs, and others localized to provinces or sites, or operating semi- independently as donor-supported programs. All agreed that these current small initiatives need to be scaled-up to become more meaningful and routine.

Community-led monitoring offers an important opportunity for community members to give feedback without fears of consequences from providers which may compromise willingness to complete surveys administered from facility staff or health authorities. The client perspective is more reliable when collected directly by themselves through CLM programs. CLM also offers an opportunity to register stigma experienced in the broader community, even though not actionable through facility QI programs.

In Cambodia, CLM was conducted online on a quarterly basis during the Covid pandemic, allowing for broader national representation. The national PSF system which captures patient experience is facilitated by the community and has some parallels with the CLM system, although more community empowerment can be advanced.

Viet Nam implements CLM in a small number of provinces but is able to conduct more frequent rounds of data collection, now reaching up to 8 every six months. In Malaysia, specific programs are led by community, such as the needle-exchange program, which collect data and report back to the National AIDS Program. Similarly, community-based testing programs involve community-based data collection that is reported back, although a formal CLM program does not exist.

The CLM program in Philippines is part of the national AIDS response funded by international donors to a community NGOs and is owned by the community. It has been implemented within a decentralized health system, making it unique among the QIS+D countries.

Some concerns about CLM were raised, notably the quality of CLM data. Most CLM programs also lack a process for accountability related to the investment in their work and results to assure its integrity for use to inform program and policy at the national level. The Country Coordinating Mechanism (CCM) offers a potential structure for review of CLM data quality.

Acceptance by providers remains a concern. In the Philippines, although laws affirm the rights of clients to express themselves, providers often have the perception that the CLM system will become a police or finger-pointing activity, requiring sensitization to overcome these concerns.

Integration: Participants suggested – and "firmly believe" - that CLM can be integrated into broader QI initiatives. Challenges to integration exist, however, especially the engagement of leaders to support of CLM, accepting CLM monitoring and willingness to be responsive to findings from CLM data. Philippines is pursuing CLM at the national level. As it is developing a national quality policy framework, the opportunity is present to integrate CLM into that policy. Opportunities exist to expand CLM to other areas of care, particularly national priority areas, such as tuberculosis and maternal child health.

In other countries, several CLM models exist in parallel, requiring alignment and standardization before integration into national policies can occur.

Overcoming resistance to accepting community data was highlighted by participants. As CLM captures the experience of people accessing services, it stands apart from quantitative clinical measurement and can be relatively unfamiliar to providers. Sensitization and engagement will be important to achieve success.

Participants noted that there were two streams of CLM related to data use. At facility level, specific facility CLM data can be integrated with other sources to evaluate areas for improvement, whereas at national level, aggregated CLM data from the country can inform national program priorities and actions.

In countries with centralized health systems, participants underscored their conviction that communities should work together with the national health authorities, local authorities, and collaboratively develop a national plan for CLM from the beginning to identify improvement priorities, and strategies to integrate CLM into QIS+D programs. This approach should be co-designed in this collaborative approach. Where multiple independent CLM programs are operating, the national program would have to take charge to coordinate a national approach and strategic plan to integrate CLM into its activities. For example, CLM would become a component of the National 3x4 Strategy in Thailand, although scale-up to all 71 provinces would be a major challenge.

In the Philippines, where the health system is decentralized, QIS+D is currently limited in scope and CLM is owned by the community, integration of data collection may be more feasible through embedding QIS+D methods into the CLM process which has a stigma module. Application of QI to CLM would necessarily be integrated into the QIS+D approach until a national HIV quality program is developed more fully.

Resources were identified as a potential barrier to integration since national budget allocations would be required to lead integration of the different CLM activities.

At facility level, the Viet Nam model has supported integration through its CLM pilots. CLM data are ideally integrated into quarterly QI meetings, together with QIS+D data. In this way, all of the data sources can inform the action plans for the next period. This triangulation allows both sets of data to be considered and community advocacy to be part of the facility QI process.

#### **Summary**

All of the countries have expressed strong commitment to CLM although must acquire or allocate resources to assure its sustainability and integration into national HIV and quality programs. Implementation will vary considerably depending on the nature of the health system and government structure. Although concerns were raised about data quality, efforts are being implemented to build capacity among community organizations to advance their skills in data collection, analysis and reporting. Finally, participants shared the common conviction that a collaborative process between community, providers and policymakers must be advanced to ensure a common understanding of CLM and to guarantee its success as a component of national systems to improve the quality of care for PLHIV and key populations.

#### **Total Facility Approach (TFA) to HIV-Related Stigma Reduction**

Presented by Laura Nyblade, Fellow and Senior Technical Advisor in Stigma and Discrimination, RTI International.

The Total Facility Approach was presented as a comprehensive methodology for addressing stigma at all levels of the health facility<sup>1</sup>. Three key principles for HIV stigma reduction form the basis of the total facility approach: **1**) address immediately actionable drivers; **2**) engage opinion leaders and create partnerships with affected groups; and **3**) centering the response on the strengths of affected groups.

The **facility environment**, namely its policies, standard operating procedures and physical space, is a key actionable driver of stigma, together with **awareness about stigma** and its ramifications, **fears of transmission** and of being identified with stigmatized groups, and the attitudes and beliefs that may be unconsciously expressed and create an unwelcoming environment.

Implementation of the total facility approach occurred in three stages: 1) **localizing the** intervention to the facility context by adapting existing assessment tools and conducting baseline surveys of staff and clients; 2) capacity building through participatory training of health facility staff and clients as joint training teams that is delivered to the facility staff; and 3) action plans developed and executed by stigma reduction champions in collaboration with facility management.

Crucial to success of the TFA are monitoring methodologies similar to QI processes, engaging facility management, and integrating stigma reduction into the broader facility culture to avoid the perception of it as an external imposition. The approach is easily modified to address KP-stigma and has been successfully adapted to address stigma towards MSM in Ghana and PWUD in Tanzania.

S+D reduction should be a component of all HIV programs and an explicit component of delivering high-quality person-centered health services. Stigma reduction can be integrated into QI processes, medical training, licensing and accreditation, and performance assessment, and incident reporting systems. Investment in S+D reduction can be framed as a clear way to achieve positive outcomes across the prevention to treatment cascade, to leverage synergies to reduce stigma across multiple conditions, to successfully engage key populations and

to strengthen existing efforts to end the epidemic and to successfully engage key populations in care.

#### **Further reading:**

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#### **Country-Specific Discussions and Insights on TFA**

Participants were asked to reflect on the current status of QIS+D related to the TFA, confronting potential barriers, and identifying strategies to overcome them. The discussions were framed around the necessity of evaluating service units comprehensively, fostering leadership support, integrating the QIS+D program with national quality efforts, and ensuring the inclusivity of consumer experiences across all service areas. Additionally, the group considered the specific issues of representative sampling within facilities, both large and small, and considered the implications of varied staffing and service areas on stigma reduction measures. This knowledge exchange was aimed at fostering a unified approach to stigma elimination in healthcare settings, ultimately advancing the overarching goal of quality, equitable care for all.

Each country was asked to consider the following questions and report back.

1. Does your country currently conduct QIS+D in the "whole facility"?

2. What are the barriers you are expecting to encounter when you expand to the whole facility? What strategies would you use to overcome these barriers? How can you engage facility leadership to support QIS+D activities (measurement and QI) in their organizations?

3. Do you review all service units in the facility? If not, which units are reviewed? How can you ensure a representative sample of HCW for the survey? What is the current sampling strategy?
4. Would you identify consumers who have used other service areas of the hospital/clinic? How do you (or would you) sample consumers to ensure representative data about stigma in with the total facility approach?

5. Is your QIS+D program integrated with the national quality program? If not, what are the concrete steps you can take to align the QIS+D program with the national quality program?

#### **Cambodia**

-Currently, QIS+D is focused mainly on HIV services. The anticipated barriers include engaging leadership at the Ministry of Health so that they understand the program and securing resources. -Strategies to overcome barriers involve advocating for the integration of S+D measures into overall QI processes and mobilizing national support. Integration should prioritize mental health, sexual health and NCDs. NCHADS will advocate for this integration.

#### <u>Malaysia</u>

-Malaysia conducts QIS+D with a total facility approach, including all service areas from registration to clinic exit points.

-Strategies for ensuring representative sampling and engagement include top-down directives, the establishment of task forces, and the use of online mechanisms for data collection. Consumer representation is targeted at 80% of PLWH in the facility.

-MOH leads this initiative with vertical alignment at state and local levels through national direction and through formal agreements between agencies. NGO participation is coordinated through the Malaysian AIDS Council for integration with the MOH

#### **Philippines**

-The Philippines lacks a national policy for quality improvement and for stigma reduction. No process for capacity building exists within the decentralized structure of the Department of Health. -Spread to the >1000 healthcare facilities will be challenging.

-Proposed approaches would include developing a national policy, enhancing human resources, strengthening partnerships with providers and community, and engaging various hospital groups for support.

#### Lao PDR

-Lao PDR applies the QIS+D surveys in the ART services in its hospitals.

-PLWH are identified from the ART clinic.

-The QIS+D program is recognized by the national "5 Goods 1 Satisfaction" program but more efforts are necessary to expand to other sectors in hospitals.

#### Viet Nam

-HIV services operate semi-independently within the health system, presenting challenges for a total facility approach.

-Efforts are focused on integrating stigma reduction into existing quality management health systems and addressing specific departmental needs.

-Strategies currently exist to integrate S+D into trainings for healthcare workers with efforts to implement through provincial health units.

#### **Thailand**

The Thai strategy to address stigma reduction in healthcare facilities includes a multi-pronged approach that involves a number of components and considerations, including:

1. <u>Investment</u>: The Ministry of Public Health Department of Disease Control aims to implement its national stigma program – 3x4 - across entire facilities. Achieving this goal, however, is hindered by the cost of investment in human resources for training and capacity-building, reflecting a critical need to balance quality and quantity.

<u>Adaptation</u> of TFA more efficiently through use of technologies such as e-learning, although challenges exist in linking e-learning interventions to effectivenss and outcomes.
 <u>Integration</u> of activities supported through different agencies, such as the Ministry of Public Health and the Hospital Accreditation (HA) Institute, to ensure alignment

4. <u>Leadership</u> engagement that enables a top-down approach for endorsement of policy and advocacy from government that includes emphasis on achieving the UNAIDS 10-10-10 targets.

5. <u>Access to real-time data</u> including comparative performance data to motivate providers throughout the facility.

6. Emphasize <u>intersectional stigma</u> to address multiple areas of vulnerability which will create broader appeal throughout the hospital.

 <u>Certification</u> including innovative disease-specific certification that embraces prevention as well as care will incentivize providers to meet standards for stigma reduction.
 <u>Monitoring and evaluation</u> of interventions (e.g., e-learning) to demonstrate effectiveness will enhance their uptake.

Key points from the Thai summary include an emphasis on strategic implementation, measuring effectiveness, and the importance of leadership in achieving comprehensive stigma reduction throughout healthcare facilities.

#### Measurement in the TFA

During discussion about measurement of stigma when applying the TFA raised a number of key issues for consideration which are noted below:

1) Participants discussed how to effectively survey large facilities and identify key service areas where PLWH and KPs access care in the facility.

2) Engagement of non-clinical staff to participate, such as administrative staff (e.g., receptionists) may require specific strategies, including support from leadership and human resource departments.

3) Sampling strategies ranged from convenience sampling to stratified sampling based on service areas. Formal sampling plans will be needed to ensure reliability of results.

4) Engaging leadership in hospitals for successful implementation was emphasized as an essential step for access to non-HIV service areas in hospitals.

#### **Implementation Challenges**

A number of challenges were identified that will need to be addressed for successful implementation of the TFA. These include:

-Engaging and sensitizing MOH Quality Departments in countries where HIV quality initiatives are separate.

-Resources for routine monitoring in hospitals.

-Including

#### **Conclusions and Future Directions:**

Moving forward, consensus was reached to strive for a universal approach that includes stigma reduction as an integral part of service delivery across all programs and services in healthcare facilities. One key element to achieve this goal will be to measure and implement stigma reduction programs that are inclusive of all diseases, thereby eliminating siloed interventions. The discussion underscored the complexity of scaling up the Total Facility Approach, considering the range of interventions, the depth of investment needed, and the importance of strategic planning to ensure both the immediate and long-term effectiveness of stigma reduction efforts.

#### **KNOWLEDGE MANAGEMENT**

Presented by Cedriann Martin, UNAIDS

Cedriann Martin reviewed the framework for knowledge management and then conducted a poll of the group to ascertain what would be useful to develop as communication products through UNAIDS.

The framework is below:



Source: Knowledge Management Training Package for Global Health Programs

The group was polled using an online survey platform to seek their opinions regarding knowledge management strategies for QIS+D that they would find useful. Participants on site from all countries responded (n=30) with representation from government officials (48%), civil society (18%) and other (33%). Responses to the survey questions are summarized below:

-Would a toolkit on applying QI methods to reduce S+D in health care be useful? Yes 93%; Not sure 7%.

-Would the toolkit need to be in your native language to be useful? Yes 83%; No 13%; Not sure 3%

-Would an online resource/website that outlines S+D QI best practices be useful? Yes 86%; No 3%; Not sure 10%.

-Would you use a dedicated Facebook page for the QIS+D Network that shared resources and facilitated exchange? Yes 43%, No 23%, Not sure 33%.

-Would you read an email newsletter for the QIS+D Network that shared resources? Yes 76%; No 3%; Not sure 20%

-If you would read a QIS+D newsletter how frequently would you like to receive it? Quarterly 60%; semi-annually 28%, annually 10%.

-Would you participate in a QIS+D Network group on LinkedIn? Yes 60%; No 30%, Not sure 10%.

-Would you participate in a QIS+D Network group on a mobile phone app? Yes 60%, No 16%, Not sure 23%.

-If you would participate in a mobile phone app, which ones would you prefer to use? WhatsApp 62%, LINE 12%, Signal 3%, Viber 15%.

When asked if respondents had other ideas about good ways to facilitate ongoing QIS+D Network communication and engagement, the words that were most commonly entered included *meeting* most often, followed by *Facebook, Network meeting, interactive platform, social media and video campaign.* Responses suggest that participants prefer most strongly to meet in person.

#### SUSTAINABILITY ASSESSMENT SUMMARY

Each country team was asked to complete the Short Program Sustainability Assessment Tool (PSAT) developed by the Brown School in the Center for Public Health Systems Science at Washington University in St. Louis. Each item is scored based on a possible total score of 7 points with explicit criteria for each score. Each domain has five items which were averaged to create a domain score. The overall score is the average of the domain scores.

Country	Environmental Support	Funding Stability	Partnerships	Organizational Canacity	Program Evaluation	Program Adaptation	Communications	Strategic Planning	Overall
Cambodia	3.8	3.4	5.2	5.2	4.4	4.6	3.0	3.6	4.2
Lao PDR	2.2	1.8	3.6	3.0	3.4	3.6	3.6	3.8	3.2
Malaysia	5.4	5.0	6.6	4.4	7.0	7.0	7.0	5.8	6.0
Philippines	4.4	2.4	5.2	3.2	3.2	2.6	2.0	3.0	3.2
Thailand	6.0	4.3	6.0	5.0	5.3	5.0	6.0	5.3	5.4
Viet Nam	3.4	1.6	5.6	1.0	4.8	4.0	3.4	2.6	3.3
Domain summary	4.2	3.1	5.37	3.6	4.7	4.5	4.2	4.0	

Each country's QIS+D program has its unique strengths and weaknesses in the different aspects of their programs as seen in the table above. Partnerships are generally an area of strength across all countries, whereas areas like communications, funding stability and strategic planning remain underdeveloped and need attention.

For reference, the tool may be found at <a href="https://www.sustaintool.org/psat/">https://www.sustaintool.org/psat/</a>

The tool offers a guide for ongoing monitoring and improvement and to guide further program development. It can be applied to any program, but a cautionary note is that the program you are assessing must be clarified so that each participant is clear about which program is being scored. It can be applied to the national QIS+D program, the national stigma program, the national quality program, or the national HIV Program. It can also be applied at facility level as a guide for program monitoring and assessment.

### **APPENDIX**

## **Participants**



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