Evidence and Learning Working Group (ELWG) Measurement Workstream

Summary Overview (April 2021)

BACKGROUND:

The **WHO Consolidated Guideline on Self-Care Interventions for Health** (2019) provided motivation to develop coordinated guidance on self-care measurement and metrics, particularly as several countries are currently adapting this guideline to promote scale-up of self-care interventions within their health system. Such guidance is needed to inform better monitoring and evaluation of self-care interventions in order to generate evidence on the feasibility and acceptability of integrated self-care programs, versus the traditional self-care intervention-specific focus; and to assess the impact of self-care on population health outcomes and prevalence of care. The demand for clearer guidance for self-care measurement was corroborated in the Self Care Trailblazer Group (SCTG) 2020 member survey as well as during the First Annual Member Meeting (Feb 2021). Specifically, SCTG members noted a demand to better articulate what to measure (for example, with respect to distribution, uptake, continuation, empowerment, and consumer experience), from what perspective (e.g., health systems, programs, and or/consumers), and how to incorporate relevant measures into routine measures such as the national health management information systems (HMIS), especially when some care happens in non-traditional outlets (e.g. drug shops, pharmacies, at home, and digital). We have broadened this mandate to encompass measurement of determinants, outcomes and population impacts of self-care.

This workstream can build on existing frameworks that address a range of self-care interventions such as **Global Self-Care Readiness Index** (a rudimentary index to assess country readiness for self-care), the **Self-Care Evaluation Framework** (a toolkit to support objective evaluation of self-care initiatives), and **Patient Activation Measures** (measures for participation of active and informed consumers). Furthermore, this workstream can leverage the plethora of measurement and metrics tools for specific self care interventions such as for HIVST, DMPA-SC, and MA.

PURPOSE:

The Evidence and Learning Working Group (ELWG) of the SCTG seeks to develop measurement and metrics guidance for self-care that builds on existing evidence, tools, and frameworks and meets the needs of national self-care stakeholders, including ministries of health and national HMIS programs. Specifically, it seeks to inform guidance around:

- **What to measure**, particularly in the following domains:
  - Determinants of self-use (e.g., empowerment, need for anonymity, access)
  - Accessibility of self-care resources (e.g., awareness, availability, cost)
  - Outputs and outcomes of self-care programs (e.g., demand, referrals, uptake, continuation, overall prevalence and quality of care)
  - Population health impacts
- **Where to measure**
  - At the individual or population level
  - At the community level
At the health systems level

- How to measure (using what indicators, data sources and data collection methods)
- Timing and periodicity of data collection (e.g., what to measure monthly, quarterly, annually, etc)
- How to integrate relevant self-care measures into routine data collection systems, specifically when care happens in non-traditional channels (e.g. pharmacies, drug shops, home, digital)?

EXPECTED OUTPUTS:

It is tentatively anticipated that two products will be generated from this work:

1. a landscape review of metrics currently in use, possibly organized by self-care product/intervention; and
2. a suite of proposed, standardized, self-care metrics, which ideally are applicable across self-care products/intervention (with some method-specific metrics as needed), along with data collection approaches (if feasible).

PROPOSED PROCESS:

The ELWG proposes a 4-step process to design, commission, and launch a self-care measurement tool in 2021-2022:

Step 1: Understand the landscape (April & May)

- Measurement Roundtable (April 29th): The April 2021 ELWG meeting will include a 70-minute Measurement Roundtable to identify the ‘common denominators’ of measurement issues across a range of self-care interventions, in order to inform what guidance ELWG could produce to address those challenges.

Dr. Kayode Afolabi, FMOH Nigeria, will open the roundtable by providing an overview of the Nigeria National Self-Care Guidelines and the specific measurement challenges they face as they move toward launching the guidelines later this year. This will be followed by short measurement summaries for 3 product-based self-care interventions and 1 self-care service: DMPA-SC (PATH); HIVST (CHAI); MA (Gynuity and Ibis Reproductive Health); and prenatal virtual coaches (Jhpiego). Finally, Holly Burke from FHI360 will present key insights on measuring empowerment and self-care based on a recently completed systematic review. Following these presentations, ELWG participants (roughly 60 pax expected in April’s meeting) can then choose to participate in one of the intervention-specific breakout rooms to explore the following issues: (1) what to measure (and, if time allows, where and how often to measure) in the following broad categories (a) determinants of self-use and accessibility of self-care (b) outputs and outcomes (c) population impacts; and (d) integrating self-care measures into routine data collection systems. The outcome of the roundtable will be a “report out” of key recommendations.

At the measurement roundtable, ELWG will solicit membership to form a sub-working group of ELWG to oversee and provide technical guidance on the subsequent steps in this process (the measurement workstream).

- Desk Review (May-July): Using the themes identified in the April Measurement Roundtable, ELWG will commission a technical brief on the ‘state of play’ in measurement for self-care interventions which should identify a range of existing indicators and gaps (in terms of measurement tools, guidance, and approaches) and discordance in indicators used across existing platforms (and how to harmonize
discordant findings across platforms and levels of data collection) that ELWG could potentially fill and why. Outcome/deliverable will be a report summarizing key findings and recommendations to inform the measurement framework.

Step 2: Define the specific output(s) that ELWG will produce (August)
- Measurement subworking group/workstream convenes to define the specific output(s) that it will produce, based on the options proposed in the roundtable and the desk review. This could be done with all ELWG members, or a subset.

Step 3: Develop selected measurement framework (Aug-Nov)
- Develop the self-care measurement framework, including recommended indicators and tools that will be used in 2022 by national self-care networks/technical working groups in Uganda, Nigeria and/or other countries overseeing the implementation of national self-care guidelines. Uganda’s Self Care Expert Group (SCEG) has already expressed interest to implement this type of tool/framework. As part of this process, the team developing this framework will convene (a) an expert group meeting with the intended users of the framework (including drawing from SCTG membership) and (b) a meeting of the subworking group of ELWG that has volunteered to support this workstream, to obtain guidance and feedback at early stages. The workstream lead will also keep the SCTG and ELWG informed of progress on this work.

Step 4: Document and Disseminate the Use of the Output (2022/2023)
- Develop case studies on the use of the self-care measurement framework in 1-2 national contexts in order to document the extent to which the framework met its intended purposes and/or may need further adaptations.

DELIVERABLES:
- Report of Measurement Roundtable and Desk Review, with recommendations.
- Draft and final self-care measurement framework, including tools and indicators (scope may evolve based on desk review findings)
- Case studies of pilots