# Localizing WHO Guidelines on Self-Care

Samasha

PROPEL

A Practical Guide From Uganda



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# **ABBREVIATIONS**

ANC antenatal care CEHURD Center for Health, Human Rights, and Development HMIS health management information systems MOH Ministry of Health NGO nongovernmental organization PrEP pre-exposure prophylaxis SBC social and behavior change SCEG Self-Care Expert Group SRHR sexual and reproductive health and rights UNFPA **United Nations Population Fund** USAID U.S. Agency for International Development WHO World Health Organization

# **O1** INTRODUCTION

### Background

Self-care is defined by the World Health Organization (WHO) as "the ability of individuals, families and communities to promote health, prevent disease, maintain health, and cope with illness and disability with or without the support of a healthcare provider" (World Health Organization, 2019). Self-care has been practiced for decades with both traditional and complementary medicine, as well as modern management of noncommunicable diseases such as diabetes. However, incorporating self-care into health policies is a relatively new concept. Most self-care interventions have been implemented as vertical programs with limited integration into the health care system; for example, while self-testing might be available for certain conditions, health providers will not accept the results of self-testing to initiate treatment. Advocates for self-care have encouraged the creation of system-wide self-care guidelines integrated into health systems at each level.

In June 2019, WHO released the <u>Consolidated Guideline on Self-Care</u> <u>Interventions for Health: Sexual and Reproductive Health and Rights</u>, which was updated in 2022 as the <u>WHO Guideline on Self-Care</u> <u>Interventions for Health and Well-Being, 2022 revision</u>. The guideline provides a people-centered, evidence-based framework, along with normative guidance, to support individuals, communities, and countries to put in place high-quality health services and self-care interventions.

In 2020, Uganda began to adapt the 2019 WHO self-care guideline to create a Uganda-specific national guideline on self-care interventions for sexual and reproductive health and rights (SRHR). The adaptation process began with the establishment of a Self-Care Expert Group (SCEG) chaired by the Ministry of Health's Director of Clinical Health Services, with support from the Assistant Commissioner for Adolescent and School Health. PSI acted as secretariat for the



SCEG, and a national self-care consultant was hired to facilitate the guideline development process. By December 2020, the SCEG had drafted the Uganda National Guideline on Self-Care Interventions for Sexual and Reproductive Health and Rights and made the strategic decision to pilot test the draft guideline at the subnational level and use the lessons learned to inform revisions to the guideline before national launch and scale-up.

### **How-to Guide**

This how-to guide, developed with support from PROPEL Health, documents Uganda's innovative policy sandboxing approach and illuminates a guideline development process that may be helpful for other countries. The sections below, organized by the five phases of the process, detail the purpose and objectives of each phase, Uganda's experience, lessons learned, and suggested activities and tool for other countries wishing to follow a similar process to develop national self-care guidelines.

# **O2** APPLYING THE UGANDA MODEL FOR DEVELOPING NATIONAL SELF-CARE GUIDELINES

### **Uganda's Self-Care Context**

Uganda is in many ways an ideal country to develop and test national self-care guidelines. Forty-four percent of Uganda's population is under age 15, just above the 42 percent across sub-Saharan Africa (Kaneda et al., 2023). The total fertility rate, defined roughly as the number of children per woman, is 5, and 36 percent of married women ages 15 to 49 use a modern method of family planning. Just under 96 percent of women receive antenatal care (ANC) from a skilled provider and over 70 percent of women are literate (Kaneda et al., 2023). These demographic characteristics and potential touchpoints with the health care system provide openings for self-care education and awareness raising.

Uganda's health system is decentralized, with much decision-making authority resting with district health leaders (Mansour et al., 2022). Districts encompass health subdistricts, local health management and provision teams, and village health teams. This system is structured around the health care provider and direct access between the client and health care workers.

Uganda has had a successful history of implementation research on self-care interventions across health areas. Contraceptive selfinjection has been considered a key pillar of increasing contraceptive availability for nearly a decade, and subcutaneous DMPA-SC injections have been available in some Ugandan districts since 2016 (Injectibles Access Collaborative, 2021). Pilot testing of a communitybased, self-collected cervical sample for HPV testing has found



self-collection to be feasible and accepted by participants in Kampala (Moses et al., 2015). Various methods for self-testing for HIV have been introduced and are being scaled up, and rapid malaria selftesting has been rolled out by the National Malaria Control Program (Ministry of Health Uganda, 2018; Mbonye et al., 2014). Each of these self-care interventions has their own guidelines and policies that were developed and implemented by health area-specific teams.

Beyond these high-profile self-care interventions, some simpler selfcare activities have long been available across the country, including at-home pregnancy tests, blood pressure testing, and urine glucose testing. Before the self-care guideline, however, these self-testing interventions lacked clear guidance on who should use them and how the results could be incorporated into the health care system. For example, a client who self-tested positive for HIV would have to be re-tested by a health facility before receiving associated medical care.

Self-care advocates in Uganda wanted to combine self-care interventions under a single policy and to refine the implementation of this policy so that it could integrate smoothly into the health system at each level.

### Uganda's Five-Phase Approach to Developing National Self-Care Guidelines

Uganda's five phase approach to developing, testing, and implementing self-care guidelines (see figure below) can help to ensure that a country's self-care guidelines are supported by national and district leadership; fit within the existing health system; and are acceptable and appropriate to health workers, self-carers, and other stakeholders.





### **Cultivate Government Ownership**

### PURPOSE

As in the development of all new government policies and programs, in the first stage of developing national self-care guidelines, cultivating the support of national leadership and coalescing civil society and development partners around a common agenda are essential. Building a self-care coalition requires a deliberate effort to socialize the self-care concept within relevant government departments; implementing partners; religious, cultural, and political leaders; and opinion leaders, including social influencers.

### **OBJECTIVES**

- Establish a group of national and international stakeholders to advocate for government support of national self-care guidelines.
- Cultivate broad, multisectoral government ownership of the selfcare guidelines process.

#### **UGANDA'S JOURNEY**

A group of development partners and civil society organizations, led by PATH and PSI with WHO, first approached the Uganda Ministry of Health (MOH) to advocate for Uganda becoming one of the first countries to create national self-care guidelines based on the WHO guideline. The MOH adopted the concept and permitted a phased approach to the development of the national self-care guidelines as a living document that would first focus on SRHR interventions before expanding to other health areas, mirroring the WHO's approach. The MOH committed to providing leadership and stewardship during the development, piloting, and scale-up of the guidelines.

In March 2020, the MOH convened stakeholders from various sectors—representing multiple health topic areas, government and nongovernmental organizations (NGOs), and public and private providers—to discuss the concept of self-care and to generate buy-in and technical oversight for the guidelines, especially those aspects that would impact multiple health departments and priorities. There was stakeholder consensus on how to structure the delivery of self-care: by building on existing successful self-care interventions (including managing non-communicable diseases, scaling up use of injectable contraceptives, and HIV self-testing) to pave the way for development of more comprehensive guidelines.

LESSONS FROM UGANDA

Have a strong justification for creating self-care guidelines in your context. When approaching the MOH or another government agency, do so with targeted justification for introducing a national self-care policy in the country. The WHO guideline includes excellent information about the benefits of self-care generally, but it will fall to the champions of this effort to develop a justification that applies to the specific context. Research the expected points of opposition and plan explanations or counterarguments to these points, many of which can be found in the WHO guideline.





**Know your resource needs.** Advocacy, coalition building, testing, and implementation require resources. In Uganda, PSI mobilized resources for the development of self-care guidelines and used them to convene initial meetings. PSI presented funding needs to the SCEG as they were identified and submitted proposals to funders as needed.

Resources required for developing, testing, and implementing the guidelines should be identified and quantified from the beginning. Be transparent with partners about what will be needed and accept contributions that are both financial and in-kind (e.g., human resources, technical assistance, etc.). Some middle-income countries or those with national health insurance might be able to fund the testing and implementation of the guidelines themselves, but resources will still be needed to grow support at the beginning.

**Foster government ownership.** In Uganda, once the government appointed leadership for the guideline development, it became the steward of the entire process, which helped to ensure success. This may not be the case in every country; the relative responsibility for developing, testing, and implementing national self-care guidelines will look different depending on context. In cases where more responsibility sits with NGOs, prioritize increasing government involvement and ownership at every step through regular briefings and sharing successes from other countries.

#### SUGGESTED ACTIVITIES

- 1. Secure stakeholder buy-in:
  - Assemble an initial group of supporters, which could include the WHO country office; United Nations Population Fund (UNFPA) country offices; UNICEF; U.S. Agency for International Development (USAID); and the United Kingdom Foreign, Commonwealth, and Development Office. These development partners have leverage within the highest offices in countries and can open the door for initial meetings.
  - Identify and map key stakeholders. Who is already an ally on this issue and can help to bring others on board? Whose support will be important in making this happen? What evidence will convince these stakeholders of the need for a national self-care policy?
  - Hold meetings with in-country and international partners to strategize on building support for self-care guidelines, including creating context-specific justifications for the guidelines.
  - Identify potential barriers and opposition and address them through advocacy presentations for government leaders that offer justification for a national self-care policy and speak across health areas.
  - Design a roadmap for how the guidelines will be developed, tested, finalized, and implemented.
- 2. Engage in high-level advocacy to build government support:
  - Understand the perspectives of high-level decisionmakers (e.g., MOH and other relevant agencies) and deliver targeted presentations to them. Present the justification and roadmap and ask for their support and partnership in developing and implementing the guidelines.
  - Request the appointment of a senior government official to serve as the self-care focal person during the process.



### **Establish a Self-Care Expert Group**

### PURPOSE

At this stage there is a need for a national coordination team that will guide and oversee the guidelines development process. This team will require a secretariat, membership, and leadership.

### **OBJECTIVES**

- 1. Establish a Self-Care Expert Group (SCEG).
- 2. Assign SCEG task teams and roles and responsibilities.

### **UGANDA'S JOURNEY**

The MOH established the SCEG, composed of technical SRHR experts responsible for guiding the process of structuring the delivery of self-care. The SCEG led the guideline development process, oversaw coordination of partners and key stakeholders, and supported continuous monitoring of self-care interventions.

The SCEG was headed by the MOH's Director of Clinical Health Services and co-chaired by the Assistant Commissioner of Adolescent and Child Health, with clear terms of reference to support and guide the introduction of the self-care package of interventions as outlined in the draft guidelines. The SCEG was comprised of representatives from line ministries and agencies (MOH; Ministry of Gender, Labour, and Social Development; National Population Council), development partners, implementing partners, academia, youth organizations, private sector, and professional associations. (See <u>Tools</u> for the SCEG terms of reference and full list of participating groups.) The MOH, with support from PSI, onboarded a national self-care consultant to guide the development and testing of the national self-care guideline and accompanying tools. **LESSONS FROM UGANDA** 

**Create an expert group with diverse expertise.** Self-care advocates need to work across health areas. Unlike many health policies, effective self-care guidelines should involve a range of health areas and cross-cutting issues, including SRHR, family planning, infectious and chronic diseases, and youth. Self-care guidelines need a primary health care integration approach. To do this, it is important to work across MOH departments and also to consider collaboration with other ministries that oversee gender, youth, and finance policies.

Although it is often efficient to work with an existing expert group or team, in Uganda, a new group composed of members representing multiple health areas and technical backgrounds was established, since no existing group included stakeholders from all relevant sectors.



If the MOH is resistant to the idea of forming a new group, they should find opportunities to involve new individuals and organizations with the existing group. New voices can contribute to the guideline development process by conducting stakeholder interviews, giving presentations at SCEG meetings, and participating in subcommittees.

**Be practical about leadership.** Involving high-level officials has benefits and drawbacks. In Uganda, the Director of Health Services was the appointed self-care focal person from the government and provided excellent leadership and stewardship. Because of his senior position, however, he had a busy schedule and was often unable to focus on the day-to-day needs of the guidelines process. Thus, he deputized the Assistant Commissioner for Adolescent and School Health to handle routine practicalities of the role.



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SUGGESTED ACTIVITIES

#### 1. Establish SCEG membership and governance structure:

- Create membership terms of reference. These should be developed and approved by the MOH, led by the self-care focal person.
- Recruit a SCEG. SCEG members should be appointed by the MOH under consultation with existing stakeholders. The membership should be multisectoral and all encompassing, including other government departments, civil society, development partners, and academia. Be sure to include implementing partners who have implemented self-care interventions in the country to enrich the selfcare guidelines development process with their experience.
- Secure a secretariat. The MOH should appoint a nongovernmental or international organization to serve as the SCEG secretariat. This organization should have a good working relationship with the MOH as well as with health implementers in the country.
- Consider a self-care consultant. The secretariat can lead recruitment of a self-care consultant with the support of other SCEG members. The consultant should have a high level of technical knowledge and experience in the health areas relevant to the self-care guidelines. This person should also be an effective facilitator, able to work with many different people and groups with varying agendas. Alternatively, this role can be taken on by an existing staff member at one of the SCEG organizations.
- 2. Form task teams and assign group roles and responsibilities:
  - Develop SCEG subcommittees or task teams to help delegate specific roles and responsibilities to SCEG members. The exact task teams can vary in response to local needs, but suggested teams are: Social and Behavior Change Communication; Quality of Care; Finance; Monitoring, Evaluation, and Learning; Supply Chain; and Human Resources. Task teams should cut across health areas and products and align with priorities for the process of developing, testing, and implementing the guidelines. SCEG members should be involved in a limited number of task teams to focus their efforts.

PHASE 4



### **Conduct a Situational Analysis and Develop Draft Guidelines**

### PURPOSE

It is important to have a complete understanding of how the guidelines will fit into the existing health care system and policies, what self-care options are currently available, and what the experience has been with self-care in the country. The new guidelines should be strongly rooted in findings from this analysis.

### **OBJECTIVES**

- 1. Increase understanding of existing policy and health system context through landscape analysis.
- 2. Develop draft guidelines.

### **UGANDA'S JOURNEY**

To develop a context-specific guideline, the national self-care consultant, with support from the SCEG, conducted a landscape analysis to understand the self-care interventions already being implemented across the country. The landscape analysis, which was summarized in the final guideline, included a mapping of existing national policies and frameworks that support self-care practice and examined any inconsistencies between policies.

A later legal and policy analysis by SCEG member organization Center for Health, Human Rights, and Development (CEHURD) examined more than 47 international and national laws, conventions, bills, guidelines, strategies, and amendment notes to identify gaps and opportunities for self-care advocacy. This analysis allowed the self-care guideline to fit neatly into various national policies and frameworks, including the SRHR and adolescent health policies; the Reproductive, Maternal, Newborn, Child, Adolescent, and Healthy Aging Sharpened Plan 2021–2026; the Family Planning Costed Implementation Plan II; Uganda Clinical Guidelines; and the Essential Medicines and Supplies Lists. (See <u>Tools</u> for a full list of international, regional, and national policies included in the CEHURD review.)

Uganda adopted all the WHO's self-care recommendations, except for self-assessing eligibility and self-management of medical abortion, due to current abortion laws in the country. Seven of these recommendations were entirely new to Uganda, including making oral contraceptive pills available without a prescription and allowing for HPV self-sampling for cervical cancer screening.

PHASE 5

The remaining practices or services were already available either nationally or in some districts. Furthermore, Uganda added several self-care solutions beyond those included in the WHO guideline that were already being provided within the health system or were in the process of being introduced. (See <u>Tools</u> for a list of self-care interventions included in the national guideline.)

The national consultant led the writing of the national self-care guideline with the support of the SCEG and oversight of the MOH. The SCEG engaged in a series of review meetings and discussions to fine-tune the guidelines. (See <u>Tools</u> for the table of contents from the Uganda guideline, the National Guideline on Self-Care Interventions for Sexual and Reproductive Health and Rights.)

LESSONS FROM UGANDA

**Hold a guidelines development meeting.** To ensure focused attention and collaboration, it may be helpful to hold a two-day, in-person meeting with the SCEG. Breakout sessions can help determine the purpose and objectives of the self-care guidelines and ensure that their wording is understood clearly by stakeholders. Day 1 should feature a detailed discussion of the self-care concept; Day 2 should focus on the purpose, objectives, guiding principles, and priority interventions of the guidelines.

The outcomes of the meeting can be used by the self-care consultant during the drafting of the guidelines.





#### SUGGESTED ACTIVITIES

- 1. Undertake a landscape analysis:
  - Support the self-care consultant to conduct a landscape analysis that includes a literature review of all current and previous self-care interventions implemented in the country; a mapping of existing policies relevant to self-care; and key informant interviews with policymakers, implementing partners, and other stakeholders.
     Findings from the analysis should be presented to the SCEG in advance of the guidelines development meeting, with highlights repeated at the meeting.
- 2. Prioritize self-care interventions:
  - Task the consultant to use the landscape analysis findings to develop clear and specific recommendations for self-care interventions for the guidelines. After seeing the landscape analysis results, the SCEG should agree upon a list of priority interventions. (See <u>Tools</u> for a complete list of interventions included in the Uganda guideline.)

### 3. Develop guidelines:

- Undertake an intentional, deliberate process to determine the purpose of the guidelines, the objectives, and the guiding principles. This process should be facilitated by the national consultant and include input from stakeholders both within and beyond the SCEG.
- The initial draft of the guidelines should be written by the self-care consultant, based on the priority interventions determined by the SCEG.
- Share the draft guidelines for comment with additional stakeholders, including political leadership within and beyond the MOH, professional bodies such as nurses and midwives' associations, allied health workers, pharmaceutical societies, laboratory technologists, community health workers, health communications experts, youth groups, and other civil society organizations.

PHASE 2



### Sandbox the Guidelines in a Learning District

#### PURPOSE

To test and adapt the self-care guidelines through a sandboxing approach.

### **OBJECTIVES**

- 1. Identify an appropriate setting for sandboxing policy changes.
- 2. Develop and test implementation tools (e.g., training materials and data collection forms) and methods.
- 3. Test implementation of the guidelines in the selected setting.

### **UGANDA'S JOURNEY**

To pilot the guidelines in a real-life setting, the SCEG used the sandboxing approach in Mukono District, located in Uganda's Central region. The lessons learned from the sandboxing process were incorporated into the final guideline.

### What Is Sandboxing?

"Sandboxing" refers to piloting/testing reforms or innovations under actual conditions in a defined space within a defined time period. Sandboxing is most commonly applied to testing new software or technologies and requires explicit parameters for testing and defined measurable outcomes but, in this case, PROPEL Health is experimenting with sandboxing policy changes to ensure policy development is responsive to an implementation context. Sandboxing is implemented in a specific area or population with appropriate supervision and safeguards in place, with the goal of proving the policy is effective or beneficial before finalizing it and applying it broadly. This approach helps to ensure that when the final policy is adopted, it will achieve its intended goals.

**Source:** Adapted from United Nations Department of Economic and Social Affairs, 2021, <u>Sandboxing and</u> <u>Experimenting Digital Technologies for Sustainable</u> <u>Development</u>. UN DESA Policy Brief No. 123.

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Mukono District was selected due to existing characteristics that would facilitate the test implementation process: a mix of urban, rural, and hard-to-reach areas; a vibrant and forward-thinking district health team; and an existing set of selfcare interventions being implemented with support from partners.

The MOH led a delegation to meet with all 11 members of the district health team in Mukono District to introduce the selfcare agenda and guideline development process and to initiate collaboration with the other district teams in testing the guideline. A follow-up meeting with 29 health facility in-charges and administration teams was held to introduce the concept of self-care and create buy-in for test implementation activities within the health facilities.

Based on agreed-upon criteria, 18 facilities were selected to participate in the test implementation representing all the health subdistricts in Mukono District. Of these, 10 were public while eight were private health facilities. Ten national and five subnational trainers were selected by the MOH and the

Mukono district health team, with consideration of their roles within the health facilities or the MOH. These participants joined a three-day training of trainers on the self-care concept, the guidelines, and the guidelines' integration into the existing health system. These trainers then worked to cascade information to health providers and other key stakeholders.

Following the training of health providers, each health facility adopted strategies for supporting individuals to practice self-care. Some of the strategies included educating individuals about self-care interventions during health education sessions at the health facilities, collaborating with village health teams to create awareness, and using the code "SC" in the registers to identify self-care clients.

### LESSONS FROM UGANDA

Set village health teams up for success. Village health teams initially participated in the same trainings and used the same training tools as more senior providers. Early on, it was realized that the village health teams would need adapted training tools with simplified language and concepts that focused on their specific role in implementing self-care education and interventions.



Ultimately, the village health teams played a critical role in facilitating the practice of self-care at the community level through integrating self-care in community health education sessions, distributing and supporting the correct use and disposal of self-testing and self-sampling kits, and referring self-care clients to health facilities for continuity of care.



#### Understand how providers will record self-care. Recording

self-care interactions (e.g., orienting a client on self-care for continuation at home, recording a self-care support visit, or noting advance provision of self-care supplies) was completed by health workers using existing recording tools at their facility, often adding the code "SC" to denote a client using a self-care method. Working with providers to develop a customized reporting tool specifically for self-care would have facilitated recording for providers and reviewing data for monitoring, evaluation, and learning efforts.

Until Uganda's health management information systems (HMIS) are updated to reflect the national guideline, the word self-carer or code "SC" can be added in the notes section at the end of the HMIS form or in the empty space after entry of client details. In the laboratory, workers can add the word "self-carer" in front of the client names or after the results are recorded.

Prioritize social and behavior change efforts. One of the most critical and most expensive—components of self-care is raising awareness and prompting new actions through social and behavior change (SBC). Channels for SBC include digital media, radio and television, peer-to-peer communication, and community engagement. For these activities, it is important to use evidence-based SBC methodology to maximize impact. Careful planning is needed to ensure that introducing self-care guidelines is not only a supply-side intervention, but includes community sensitization, social norms change, and demand creation.

Because SBC can be expensive, use existing channels for awareness raising among potential self-carers. Uganda found it cost-effective to use the existing health facility triage and planned health education talks on ANC, immunization, and other topics.



Focus on easiest-to-reach individuals for testing the acceptability of interventions. For self-care programming, the easiest-to-reach clients are ones who already visit health facilities for various reasons. Encourage providers to use existing health education talks between providers and potential self-care clients, including those on ANC and immunizations. Reaching these existing clients with self-care information can mean reaching a high proportion of the health-seeking population.

Similarly, there are numerous community health workers providing villages with SRHR information and services. Building on their existing engagement with the community with self-care information sessions is effective and requires fewer investments than creating new outreach programs.



#### SUGGESTED ACTIVITIES

- 1. Select sandboxing site(s) and begin partnership:
  - Consider how a potential site reflects the various contexts in your country, including urban, peri-urban, rural, and hard-to-reach settings, and the interest in testing new approaches by local leaders (including district health teams).
  - Select a sandboxing site(s) with a competent and committed administration.
  - Determine whether any elements of the self-care guidelines are currently in place at the sandboxing site(s) and whether there are any existing programs to serve as partners. For example, health literacy initiatives and programs to increase provision of SRHR commodities through pharmacies can facilitate the uptake of self-care interventions.
  - Hold an initial meeting with the sandboxing site administration and present to them the self-care concept, the objective and purpose of sandboxing policies, the implementation plan, and the roles and responsibilities of each party.
  - Request that a senior member of the local administration be appointed as the district self-care focal person and create a coordination team to play a supervision role. Ensure that at least two members from this subnational coordination team attend the ongoing SCEG meetings.
  - Build capacity for and social acceptance of self-care programming through orientation of subnational local leadership (political and administrative); religious and opinion leaders, including social influencers on social, print, and television media; adolescent and youth groups; and community-based groups.

### 2. Plan sandboxing:

- Select a broad range of facilities within the sandboxing site(s) for implementation of the pilot. Facilities should represent the private and public sectors and NGOs and include pharmacies, clinics, and hospitals.
- Allocate between six months and one year for the implementation of the sandboxing. A longer sandboxing period gives you more time to see the impacts of the guideline.

#### 3. Create provider training materials:

- Support the self-care consultant, with input from SCEG members, to develop a training manual that covers self-care concepts, the details of the guidelines, and how to implement the self-care interventions at each level.
- Consider developing a separate, less-technical training tool for community-level providers, such as village health teams or community health workers.

#### 4. Train health providers:

- Hold a training of trainers, followed by multiple cascading trainings for individual facilities and providers.
- Ensure that all training sessions cut across health areas and focus on self-care as a systems approach.

- Consider offering continuing medical education credits to providers to incentivize participation in self-care training.
- Ensure that trainings reach a broad swath of the health services delivery community, including doctors, nurses, midwives, facility administrators, pharmacists, village health team members, health assistants, peer educators, religious and cultural leaders, and medical association members.

#### 5. Emphasize social and behavior change:

- Prioritize SBC approaches that promote success from the bottom up (community awareness and support) and from the top down (provider acceptance and participation).
- Ensure that community-focused SBC activities raise awareness of the benefits of self-care, the self-care options to be available under the guidelines, and the places self-care interventions can be accessed. These activities can also serve as opportunities to improve health literacy and boost individuals' confidence in their ability to use self-care.
- Include radio or television talk shows and in-person community events, such as intergenerational dialogue between community leaders and young people, in SBC efforts.

### 6. Collect monitoring and evaluation data:

- Task the SCEG monitoring, evaluation, and learning team with developing a framework for measuring the success of the guidelines implementation and each of the priority interventions.
- Include measures of provider and client experience and uptake of self-care interventions in indicators to measure the success of the implementation. Be sure to develop a realistic and cost-effective plan for collecting this information. It is likely more efficient to collect data from providers, but client data are essential for illuminating the full impact of the interventions. (See Tools for an illustrative list of monitoring and evaluation indicators.)
- Ensure the subnational coordination team and SCEG each conduct regular site visits for supportive supervision and data collection. These visits create an opportunity for facility staff to inform the coordination team about what is working well at their location and potential improvements. After each visit, teams should meet to agree on lessons learned across facilities that can be shared to improve implementation at under-performing sites.
- Collect data through:
  - Provider interviews during monthly and quarterly supportive supervision visits.
  - Facility exit interviews with clients.
  - ► Facility records of self-care interactions and acceptance by clients.
  - Key informant interviews with leadership at the health facilities.

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### **Revise and Finalize the Guidelines**

### PURPOSE

Before final approval of the guidelines, it is necessary to incorporate lessons learned from the sandboxing activity into the guidelines text. The guidelines will then need additional approval from relevant government agencies before being implemented nationwide.

### **OBJECTIVES**

- 1. Incorporate lessons learned before scale-up. Update the guidelines to reflect what was learned from the sandboxing.
- 2. Obtain government approval on updated guidelines.
- 3. Finalize the guidelines and implement at the national level.

### **UGANDA'S JOURNEY**

Learnings from the sandboxing were used to revise and update the guidelines for the Ugandan country context.

Based on results from the sandboxing, many edits—both minor and major—were made to the list of interventions before the guideline was finalized. See table for illustrative examples of these changes.

### Table. Example Modifications to Self-Care Interventions Included in the Uganda Guideline

Sandboxing Result	Guideline Modification
The color changes in standard urine test strip for detecting infections can be difficult to read and interpret. At least 60% of infections in patients with persistent or chronic infections are missed.	The urine dipstick was removed from the list of self-care interventions.
The initial HIV test offered (Determine) was found to be unsuitable for self-care because it is labeled as a professional test and the HIV test logarithm requires a confirmatory test.	Determine was removed and replaced with screening tests such as OraQuick, INSTI, and SURE CHECK, which are more suitable for self- testing.
The malaria test (mRDT) offered was found to be a professional test and impractical for self-care. Additionally, each pack of 25 test trips only comes with one buffer, making it hard to share amongst self-carers.	Malaria testing was removed from the list of self- care interventions.



Before dissemination and implementation of the final guideline, the updated draft went through various MOH levels for approval, including the Family Planning/Reproductive Health Commodity Security Working Group, the Maternal and Child Health Working Group, the Medicines Procurement and Management Working Group, and the senior management team.

#### LESSONS FROM UGANDA

**Consider potential roadblocks with private facilities.** Health providers from private facilities were included in the same trainings as public facility providers. Many of these private providers reported that their supervisors would not allow them to implement many aspects of the self-care guideline out of concern that self-care would lead to reduced profits. Some especially enthusiastic private facility providers chose to implement certain self-care interventions, but these activities were not integrated into the private facility health system and were not recorded. Working more closely with the owners of private facilities from the beginning to convince them of the benefits of self-care, including increased efficiency, may have increased private facility support.



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Use education and SBC to combat provider resistance. In Uganda, sandboxing the self-care guidelines revealed that health facilities managed by lower-level health professionals (including nurses and clinical officers) had a higher uptake of self-care than facilities managed and staffed by medical doctors. It was discovered that most medical doctors had reservations about self-care, believing that all clients must first meet with a provider before undertaking self-care. In practice, some self-care interventions (such as HIV testing and aspects of ANC) do require an initial and/or follow-up meeting with a provider, while others (including some family planning methods) can be administered safely and effectively without provider involvement.

Address this misinformation with targeted efforts to change doctor attitudes toward self-care. This process should be informed by evidence-based SBC and provider behavior change methodologies and include participation from national health professional bodies. Information for providers should stress that self-care does not mean that participants do not use the health system—in fact, clients practicing self-care may actually participate more in the health system.

As stated in the WHO guideline, "self-care interventions must be an adjunct to, rather than a replacement for, direct interaction with the health system."

PHASE 4

PHASE 5

**Don't overlook supply issues.** Results show that the availability of self-care products significantly determines the practice of self-care among individuals. Unsurprisingly, the health facilities that had self-care products in stock had more self-carers than those with stockouts of self-care products. In Uganda, the SCEG had decided not to give self-care commodities directly to the facilities but engaged the MOH to include the commodities on the essential medicines list and provide them nationwide.



#### SUGGESTED ACTIVITIES

- Apply lessons learned to the guidelines draft and validate final guidelines with the SCEG:
  - Have the self-care consultant synthesize and share suggested updates to the guidelines with the SCEG and other stakeholders.
  - Be sure to include both changes to the list of self-care interventions included, and changes to the methods of implementing these interventions, in guidelines revisions.
- 2. Obtain government approval and implement guidelines:
  - Note that the approval process and the required approval bodies will vary by country. Approval bodies may include the MOH, specific agencies within the MOH, and other ministries or governing bodies.



The following tools are based on the work done in Uganda to develop and test the self-care guideline. They can be adapted and used as worksheets for your self-care guidelines process or simply used for reference.

### **Identifying Stakeholders**

Use this table to identify stakeholders for outreach and plan outreach activities during Phases I and II. The same table can be used to plan stakeholder outreach within your chosen sandboxing site.

Group or Individual	Contact Information	Existing Relationships	Established Knowledge or Views about Self-Care	Potential Role in Self-Care Guidelines Development and Testing
Name of organization or individual for outreach	What is the best way to reach this contact?	Existing relationships with this movement, project, or other stakeholders	What do you know about their knowledge or acceptance of self-care? Have they ever advocated for or against?	How could they help? Alternatively, how might they stand in the way?
Example: MOH; ABC NGO		<b>Example:</b> Three contacts in adolescent health division. Existing stakeholder is member of family planning working group with technical officers.	<b>Example:</b> Director has supported expansion of contraceptive self-injection.	<b>Example:</b> Long-standing relationships with district health teams. Experienced with policy writing.

### **Forming SCEG and Task Teams**

# The National Self-Care Expert Group (SCEG) Terms of Reference (October 2020)

### BACKGROUND

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Self-care, while not new, is becoming firmly embedded within the larger global health and development agenda with increasing relevance for health systems. Self-care interventions, particularly in the realm of sexual and reproductive health and rights (SRHR), have transformative potential to increase individuals' autonomy in making decisions about their own care, strengthen countries' health systems, and ultimately pave the way toward universal health coverage.

The World Health Organization defines self-care as the ability of individuals, families, and communities to promote health, prevent disease, maintain health, and cope with illness and disability with or without the support of a health care provider. In 2019, the WHO developed and launched the Consolidated Guidelines on Self-Care Interventions in Health for Sexual and Reproductive Health and Rights, which seeks to facilitate coordination of self-care interventions and call for adoption of national policies to usher in the transformative era.

### **DEFINING SELF-CARE IN UGANDA**

The Ministry of Health and partners in Uganda have successfully rolled out several individual self-care interventions for SRH including: HIV self-testing, oral pre-exposure prophylaxis (PrEP) for HIV prevention, self-administered injectable and emergency contraception, pregnancy self-testing, condoms, and self-awareness.

Self-management	<ul> <li>Self-injection (DMPA-SC)</li> <li>Emergency contraceptive pills over the counter</li> <li>Mama kit – improving care for and prevention of postpartum hemorrhage</li> </ul>
Self-testing	<ul> <li>HIV self-testing</li> <li>HPV self-sampling</li> <li>Pregnancy testing; couples' infertility</li> </ul>
Self-awareness	<ul> <li>Digital apps for SRHR, e.g. Family Connect</li> <li>Education through health system: health workers, village health teams</li> </ul>

As more self-care products and technology are introduced in the SRHR space and others scaled up, well guided and coordinated implementation is critical, and the operational environment needs to be attuned to facilitate advancement of interventions.

### **Roles of the SCEG**

### PURPOSE

Accelerate the adoption of the WHO self-care guidelines with a country-specific costed implementation framework for scalable SRHR self-care interventions and innovations.

### **OBJECTIVES OF THE SCEG**

- 1. To bring together experts to advise the Ministry of Health on SRHR self-care implementation.
- 2. To guide the development of the guidelines and costed implementation framework for SRHR self-care.
- 3. To coordinate stakeholders in the implementation of SRHR self-care.
- 4. To promote SRHR self-care policy change.
- 5. To mobilize resources for implementation of SRHR self-care.

### CONVENER

The Director Clinical Services, supported by the Commissioner Maternal and Child Health and/or the Commissioner Reproductive Health Division. (The convener holds the responsibility of mobilizing the SCEG members and providing strategic leadership to ensure achievement of the purpose of the group.)

### **CO-CHAIR**

Commissioner Reproductive Health Division and/or Commissioner Adolescent and School Health or as appointed by the convener. (The co-chair's role is to host the SCEG engagements and guide the discussions during SCEG meetings.)

### SECRETARIAT

PSI Uganda with support from the WHO. (The secretariat provides technical support to the SCEG and may also hold the responsibility to maintain records of SCEG engagements.)

### **MEETING FREQUENCY AND TERM**

Regular monthly meetings (unless otherwise determined).

### FINANCIAL AND COORDINATION SUPPORT

Anticipated to be provided by PSI Uganda through Delivering Innovation in Self Care (Children's Investment Fund Foundation) and interested partners. Support is dependent on receipt of donor funding. Individual SCEG members may be asked to assist in guiding specific efforts.



### COMMUNICATION

The SCEG will share minutes for actions among the group, within the technical working groups, and among other stakeholders appropriately.

### MEMBERSHIP

The SCEG will consist of organizations and where necessary, co-opt members.

### **TERMS OF MEMBERSHIP**

Up to 25 members will be nominated to participate in the SCEG for a period of two years, renewable. The SCEG will comprise representatives from the following entities:

- 1. The Ministry of Health (R&I division, ADH&SH division, pharmacy department, nursing department, DHO and ADHO representatives).
- 2. H6 Development Partners representation (WHO, UNICEF, UNFPA, USAID).
- Nongovernmental organisations: PSI, FHI 360, PATH, WRA, Planned Parenthood Global, Samasha, Living Goods, Marie Stopes Uganda, Reproductive Health Uganda, USAID FPA, CHAI, Mildmay Uganda, Center for Health, Human Rights and Development (CEHURD), youth organizations (RAHU, PHAU).
- 4. Academia: Makerere School of Public Health.
- 5. Pool of members to be co-opted as needed: Ministry of Health Planning department, NMS, JMS, NDA, CPHL, ACP.
- 6. Other government line ministries: Ministry of Gender Labour and Social Development (MoGLSD), Ministry of Education and Sports (MoES), uniformed services (military, police, prisons, ICT ministry).
- 7. Religious and cultural leaders.

### **SCEG Membership Planning Tables**

Use this table to plan membership in a Self-Care Expert Group. Remember to include members from each of the sectors listed.

### Leadership

Examples (from Uganda): Director of Clinical Health Services (MOH); Assistant Commissioner of Adolescent and Child Health (MOH)

### **Line Ministries and Agencies**

**Examples (from Uganda):** MOH; Ministry of Gender, Labour, and Social Development; National Population Council of Uganda. Other examples may include: national drug or pharmaceutical authority, youth-focused ministries, Ministry of Finance.

### **Development Partners**

Examples (from Uganda): WHO; UNICEF; UNFPA; USAID

#### **Implementing Partners**

Examples (from Uganda): PSI; FHI 360; PATH; White Ribbon Alliance; People Performance Group; Samasha Medical Foundation; Living Goods; MSI Reproductive Choices; Reproductive Health Uganda; Pathfinder International; Clinton Health Access Initiative; Mildmay Uganda

#### Academia

Examples (from Uganda): Makerere University School of Public Health

### Young People

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Examples (from Uganda): Reach a Hand Uganda; Public Health Ambassadors Uganda

Use the table below to plan task team organizational leadership and membership. Add different or additional task teams as appropriate.

Social and Behavior Change	Quality of Care	Finance

Monitoring, Evaluation, and Learning	Supply Chain	Human Resources

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### Legal and Policy Mapping on Self-Care

### **International and National Policies Reviewed**

### Summary list of international laws, conventions, bills, guidelines, strategies, and amendment notes included in review:

- ▶ UN International Covenant on Economic Social and Cultural Rights (ICESCR).
- General Comment No. 14 on the Right to the Highest Attainable Standard of Physical and Mental Health.
- General Comment 22 of 2016 on the Right to Sexual and Reproductive Health and Rights.
- ▶ UN Convention on the Rights of the Child.
- General Comment No. 15 of 2013 on the Right of the Child to the Enjoyment of the Highest Attainable Standard of Health.
- General Comment No. 5 of 2003 on General Measures of Implementation of the Convention on the Rights of the Child.
- ▶ UN Convention on the Rights of Persons With Disability.
- General Comment No. 5 of 2017 on the Right to Live Independently and Be Included in the Community.
- ▶ UN Convention on Elimination of All Forms of Discrimination Against Women (CEDAW).
- Convention on Elimination of All Forms of Discrimination Against Women (CEDAW) General.
- ▶ Recommendation No. 24 on Article 12 of the Convention (Women and Health).
- World Health Organization (WHO) Consolidated Guidelines on HIV Testing Services 2019.
- World Health Organization Consolidated Guidelines on Self-Care Interventions for Health.
- ▶ UN Sustainable Development Goals.

- > African Charter on Human and Peoples' Rights.
- Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa (Maputo Protocol).
- General Comment No. 2 on Article 14 (1) (a), (b), (c), and (f) and Article 14 (2) (a) and (c) of the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa.
- African Commission Principles and Guidelines on the Implementation of Social and Cultural Rights in the African Charter on Human and Peoples' Rights.
- East African Community HIV and AIDS Prevention and Management Act, 2012.
- ▶ East African Community Sexual and Reproductive Health Rights Bill, 2017.

### List of Uganda national laws, policies, strategies, plans, and guidelines included in review:

- The Constitution of the Republic of Uganda, 1995 (as amended).
- ▶ The National Drug Policy and Authority Act, Cap 206.
- The Penal Code Act of Uganda, Cap 120.
- ▶ The Traditional and Complimentary Medicines Act, 2019.
- Uganda National Bureau of Standards Act, Cap 327.
- ▶ The Electronic Transactions Act, 2011.
- The HIV Prevention and Control Act, 2015.
- The Children's Act, Cap 59.
- Children's Amendment Act, 2015.
- Data Privacy and Protection Act, 2019.
- ▶ The Patients Charter.
- ▶ The National Health Insurance Bill, 2019.
- Uganda National Policy for Public Private Partnerships in Health (July 2005).
- National Population Policy (June 2018).
- Adolescent Health Policy Guidelines and Service Standards (May 2012).
- Reducing Maternal Morbidity and Mortality From Unsafe Abortion in Uganda Standards and Guidelines (April 2015).
- Uganda National Self-Care Guideline for SRHR (December 2020).
- MOH Uganda Health Sector Strategic and Investment Plan (2010/11–2014/15).
- Uganda National eHealth Policy (November 2016).
- National HIV Testing Services Policy and Implementation Guidelines (October 2016).
- ▶ The National Policy Guidelines and Service Standards for SRHR (February 2006).
- Guidelines for the Uganda National Health Laboratory Hub and Sample Transport Network (September 2017).
- Cervical Cancer; Information, Education, and Communication Booklet for Health Workers (2017).
- Uganda Vision 2040.

- Third National Development Plan (NDPIII) (2020/21–2024/25).
- National Medicine Policy (July 2015).
- ▶ Health Sector Development Plan (2015/16–2019/20).
- National Comprehensive Condom Program Strategy and Implementation Plan (2020– 2015).
- The National HIV and AIDS Strategic Plan (2020/21–2024/25).
- Reproductive, Maternal, Newborn, Child, Adolescent, and Aging Draft Sharpened Plan 2 for Uganda (2020/21–2025/26).
- National Sexuality Education Framework (May 2018).
- National Family Planning Costed Implementation Plan (2020/21–2024/25).
- Third National Health Policy Under the Theme: "Towards Universal Health Coverage."

### **Prioritizing Interventions for Guidelines on Self-Care**

	Self-Care Priority Areas			
	Antenatal Care	Family Planning	HIV/Sexually Transmitted Infections	Post-Abortion Care
Self-awareness	<ul> <li>Specific health information per age group (10-19 and 20+)</li> <li>Postpartum family planning</li> <li>Post-abortion family planning</li> <li>Gender-specific considerations</li> <li>Elimination of mother to child transmission (eMTCT) medicines</li> <li>Birth preparedness plan</li> <li>Danger signs</li> <li>Exercise and nutrition</li> <li>Insecticide-treated net use</li> <li>HIV prevention and PrEP</li> <li>Breastfeeding</li> </ul>	<ul> <li>Specific health information for women by reproductive age group, information for males</li> <li>Menstrual health</li> <li>Facts about family planning methods, including side effects</li> <li>Fertility awareness</li> <li>The individual reproductive health system</li> <li>Use of digital platforms and hotlines to access SRHR information, services, and products</li> </ul>	<ul> <li>Specific health information by age group (10-19 and 20+) on STIs and HIV</li> <li>Mode of transmission</li> <li>HPV vaccination</li> <li>Hepatitis B vaccination</li> <li>Preventive measures (e.g., ABC<sup>+</sup>, circumcision, PrEP, PEP<sup>‡</sup>, eMTCT, counseling, and information)</li> <li>HIV testing and management (adherence, appointment keeping, self-referral, etc.)</li> <li>Information on SGBV and collection of forensic evidence</li> </ul>	<ul> <li>Specific health information for women of reproductive age group</li> <li>Information for males</li> <li>Causes, risks, and prevention</li> <li>Access to services and referral</li> <li>Linking post-abortion care to family planning</li> <li>Return to fertility</li> <li>Triggers for self-referral</li> </ul>
Self-testing	<ul> <li>Random blood sugar testing</li> <li>Blood pressure measurement</li> <li>Weight and height measurement</li> <li>Urine HCG (pregnancy testing)</li> <li>HIV self-testing for both men and women</li> <li>Breast self-examination (screening, testing)</li> </ul>	<ul> <li>Urine HCG (pregnancy test)</li> <li>Blood pressure measurement</li> <li>Weight and height measurement</li> <li>Random blood sugar testing</li> <li>Home-based ovulation predictor kit</li> </ul>	<ul> <li>HIV self-testing, oral HIV testing (screening test)</li> <li>HPV self-sampling</li> <li>Gonorrhea and chlamydia self-sampling</li> <li>Trichomonas vaginalis: self-sampling for women and first catch urine for men</li> </ul>	
Self-management	<ul> <li>Folic acid (pre-conception care and the first trimester)</li> <li>Iron (Fe)/folic acid (in pregnancy)</li> <li>Expanded clean delivery kit</li> <li>Magnesium trisilicate</li> <li>Treated mosquito nets</li> <li>HIV prophylaxis (for exposed newborn)</li> </ul>	<ul> <li>Self-injection (DMPA-SC)</li> <li>Oral contraceptive pills over the counter up to three months' supply</li> <li>Emergency contraceptive pills</li> <li>Self-referral for management of side effects</li> <li>Use of condoms both male and female</li> <li>Cycle beads</li> </ul>	<ul> <li>Correct and consistent use of condoms, both male and female</li> <li>Adherence to anti-retroviral treatment including PrEP, PEP, and nutrition</li> <li>Appointment keeping and self-referral</li> <li>Dapivirine vaginal ring</li> </ul>	<ul> <li>Post-abortion family planning</li> <li>Self-referral</li> <li>Adherence to treatment</li> </ul>

Self-care interventions to be newly available in Uganda are **bolded**.

<sup>+</sup>Abstinence, Be faithful, and Correct and consistent condom use <sup>‡</sup>post-exposure prophylaxis

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### Illustrative List of Indicators for Sandboxing Monitoring and Evaluation

In addition to tracking actual instances of self-care uptake, the Uganda team tracked measures related to creating an enabling environment for a self-care guideline. Use the intermediate outcomes and questions below to develop country-specific indicators for tracking the enabling environment in your sandboxing site or country.

Intermediate Outcomes	Measured by	Indicators
Individuals and communities are empowered to seek self-care	Level of knowledge	
	Level of skill in self-care	
	Health autonomy (who makes decisions)	
	Health literacy	
	Level of self-care practice	
	Level of social support	
Health systems are strengthened to support self-care	Perceived social norms	
	Levels of social action/community access	
	Willingness to support self-care by health providers (public and private)	
	A functional self-care client data capture system established	
	Level of compliance/buy-in to the self-care guidelines and policies (providers, district leaders, and individuals)	

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