SELF-CARE
TRAILBLAZER
GROUP

MEASUREMENT OF SEXUAL AND REPRODUCTIVE HEALTH SELF-CARE

CHALLENGES AND OPPORTUNITIES

Summary of findings from a landscape review
Evidence and Learning Working Group (ELWG)

BACKGROUND

Self-care is among the most promising new approaches to improve health and well-being, as it allows individuals to become agents of their own health, reduces the burden on limited and strained health care systems, and has the potential to increase equitable access to care and contribute to the achievement of universal health coverage (UHC).

The World Health Organization (WHO) defines self-care as "the ability of individuals, families, and communities to promote their own health… with or without the support of a health worker."[1] Self-care interventions, as defined by WHO, include "medicines, counseling, diagnostics and/or digital technologies which can be accessed fully or partially outside of formal health services. Depending on the intervention, they can be used with or without the direct supervision of health workers."[2] Self-care interventions are well-suited for the delivery of SRH care, because individuals, especially those in low- and middle-income countries (LMICs), may lack access to affordable sexual and reproductive health (SRH) care or may not use facility-based SRH services for fear of being stigmatized.

Measurement of self-care interventions is important to identify what works and what requires change. However, a fundamental difficulty of SRH self-care interventions is that the very feature that defines self-care is also what makes it hard to track and measure aspects of their users' journeys: By design, much if not all of a user's self-care experiences take place outside of the formal health system, where data on health service and outcome indicators are typically collected. While self-care is not a new phenomenon, codified national and global SRH self-care guidelines are still nascent, as are effective strategies for monitoring and evaluating these programs.

To address this gap, the Self-Care Trailblazer Group's Evidence and Learning Working Group (ELWG)[3] commissioned the International Center for Research on Women (ICRW) to conduct a landscape review of SRH self-care indicators. ICRW conducted a literature review and in-depth interviews with key informants involved in SRH programs in Sub-Saharan Africa that focus on self-care interventions. The review focused on self-managed abortion, self-administered hormonal contraception, and HIV self-testing, because those are among the most topical self-care issues that confront the SRH community in many Global South contexts. This summary highlights challenges in establishing and collecting data on SRH self-care indicators, with a focus on ICRW's findings. It also provides illustrative examples of self-care indicators and concludes with recommendations for how to move toward building and collecting data on a consolidated set of measures on SRH self-care.

[1] WHO. (2021). WHO guideline on self-care interventions for health and well-being. https://apps.who.int/iris/rest/bitstreams/1356501/retrieve
[2] WHO. (no date). Self-care interventions for health. https://www.who.int/health-topics/self-care

[3] The ELWG contributes to, develops, and promotes evidence to fill gaps in information to accelerate, scale-up, and sustain the policy and practice of self-care as an avenue to achieve UHC. Evidence and Learning Working Group : PSI

CHALLENGES TO ESTABLISHING AND COLLECTING DATA ON SELF-CARE INDICATORS

ACROSS SRH SELF-CARE INTERVENTIONS

A fundamental challenge to developing and consolidating indicators related to SRH self-care is the lack of consensus on exactly which activities fall under the umbrella of self-care. Even for widely recognized self-care interventions, there is also a lack of consensus on the best indicators or measures for monitoring and evaluating interventions. Other broad challenges include:

- Data collection on self-care indicators often happens through **parallel systems** in the public sector, private sector, and community, and sometimes as part of defined programs or studies; harmonizing indicators and consolidating data from different entities with different purposes is especially challenging.
- Some SRH self-care interventions are components of **larger interventions**, and indicators specific to self-care are not always specified.
- Facility-based indicators related to self-managed care do not capture self-care that happens fully outside of the healthcare system. Activities **outside of the formal health system** are often poorly tracked.
- A growing number of interventions are leveraging **digital platforms** as a means of supporting self-care; defining relevant outcomes and corresponding metrics, and integrating data from these platforms into tracking systems is becoming increasingly critical.
- Ensuring that self-care reduces inequities in access to quality care requires **disaggregation** of indicators (e.g. by age, urban/rural place of residence, etc). This places even more demands on data collection systems, such as health management information systems (HMIS), which already struggle to collect a large volume of information.

The extent to which indicators have been developed, tested, and harmonized varies widely across specific SRH interventions and even across stages of the self-care journey.

SELF-MANAGED ABORTION

Of the SRH interventions reviewed, indicator and measurement frameworks were the least well-developed for abortion self-care. The WHO's 2022 safe abortion guidelines endorse safe, self-managed abortion using WHO-recommended drug regimens,[4] and these guidelines should pave the way to developing a roster of indicators pertaining to self-managed abortion. But the following challenges are likely to persist:

- **Legal restrictions** on abortion and abortion-related stigma in many low-resource countries pose the biggest obstacle to developing programs and their corresponding metrics, and to collecting information on key indicators for self-managed abortion. This affects data collection at the facility level as well in population-based surveys.

[4] WHO. (2022). Safe Abortion Guideline. https://apps.who.int/iris/rest/bitstreams/1394380/retrieve

- **Different methodological approaches** have been developed to improve abortion reporting in surveys, and the findings from them are not necessarily comparable.
- There appears to be a particular dearth of indicators on **awareness** of safe, self-managed abortion options and services, the **demand** for these services, and on the prevalence of **self-testing** for pregnancy (i.e., through at-home pregnancy tests), which is useful for assessing whether one may be in need of an abortion.

SELF-ADMINISTERED HORMONAL CONTRACEPTIVE

Contraceptive methods provided as part of self-care interventions include various forms of oral contraceptives and emergency contraception, as well as the more recently developed self-injectable subcutaneous depot medroxyprogesterone acetate (DMPA-SC). Several hormonal contraception self-care indicators and metrics have been tested and are at various stages of implementation and adoption across countries.[5] Key challenges identified in this process include:

- Facility-based metrics on contraceptive self-care visits or contraceptive supplies distributed do not necessarily correspond directly with population-based data on the number of users or number of months of contraception conferred. It is not known how many people initiate or continue use **after leaving a facility** or whether methods are used properly (for example, whether injections are administered at appropriate intervals).
- Most self-injection programs are **not yet implemented on a large scale** and sample sizes of population-based surveys in intervention geographies are not sufficient to capture program outcomes or to cross-check with data collected by programs or by HMIS.
- Though approaches to collecting data from pharmacies—where many users obtain resupplies—have been tested,[6] countries continue to experience challenges tracking and integrating data on sales of contraceptives in the private sector, including pharmacies and drug sellers, into their national HMIS.

HIV SELF-TESTING (HIVST)

HIV self-testing is perhaps the self-care technology for which metrics are most well-established. Indicators related to HIV self-testing have been integrated into national HMIS in a number of countries. Some countries also have monitoring and evaluation frameworks for HIV self-testing led by national agencies responsible for HIV/AIDS programming, and tracking of HIV self-care is being done at various levels (e.g., the health facility and the community). Nevertheless, challenges in employing HIVST metrics remain:

- The private and public sectors have parallel data collection systems, and there exist challenges in tracking **individuals who are referred** from private to public sector, or from public sector to other sources of care. For example, data on test **kits distributed** at pharmacies are not typically integrated with data from the national HMIS.
- Routine data systems for tracking whether clients who self-test receive **follow-up care**—that is, preventative care for HIV-negative individuals and treatment for those who test positive—remains challenging.
- It is not clear whether HIV self-testing is a cost-efficient strategy for identifying HIV-positive individuals for treatment. **Tracking of costs** within and outside health facilities are needed to ascertain overall costs and how the costs are distributed, and to compare costs of different testing strategies.
- **Disclosure** among couples after HIVST, and adverse events after disclosure, are not well-tracked.

[5] E. Sedlander, Self-Injection Learning Exchange, personal communication, May 2022.
[6] https://www.fhi360.org/sites/default/files/media/documents/resource-cba2i-handbook-addendum.pdf

ILLUSTRATIVE SELF-CARE INDICATORS

Annex 1 provides illustrative examples of indicators for each of the interventions covered in this report. These are further organized by the key stages or domains of the self-care journey:

- awareness of self-care options
- preference for self-managed options
- access to self-care
- use of self-care
- quality of self-care and user experience
- outcomes and linkages to health systems
- inequities in all the above

It further identifies typical data sources of these indicators (primarily health management information systems, facility-based surveys of providers or clients and population-based surveys.)

CONCLUSIONS

Growing momentum for supporting safe and effective SRH self-care through health systems has led to a proliferation of approaches to self-care measurement. This diversity of approaches presents opportunities for innovation and "cross-pollination" of solutions across self-care areas, but has also resulted in a lack of standardized and consolidated metrics across programs, contexts, and intervention types. A fundamental challenge in the measurement of any self-care intervention is the limited or lack of interaction of users with the health system, where most routine data collection takes place. Another is that clients might move between sources of care—such as the private sector, public sector, community health workers, and virtual care—and methods are not in place to track users to avoid double counting of clients served. Given these challenges, population-based surveys may be best placed to track self-care. Findings from population-based surveys could also be used to validate health systems data and triangulate findings (for example, with data on characteristics of users coming from one source, and incidence of self-care coming from another).

Monitoring and evaluation frameworks and indicators have been developed for HIV self-testing and, to a somewhat lesser extent, self-administered hormonal contraception; however, clear and comprehensive measurement frameworks focused on self-managed abortion were not found. Across the interventions in this review, there appears to be a dearth of metrics related to barriers and facilitators to using self-care, awareness and accessibility of SRH self-care resources, the cost of SRH self-care interventions, and the effects of self-care on equitable access to quality care.

[7] WHO. (no date). Self-care interventions for health. https://www.who.int/health-topics/self-care

RECOMMENDATIONS

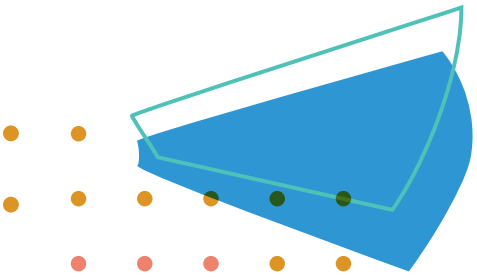
Some recommendations from stakeholders on SRH self-care indicators are specific to the issues surrounding self-care; others were relevant to health care broadly, but they bear emphasis because much of the work on developing standardized metrics for self-care is still ahead. These recommendations include:

- A roster of **well-defined indicators**, with an emphasis on those for which data collection is feasible, should be developed and applied across intervention types and sectors, to increase efficiency and comparability of data across programs and data sources.
- For some indicators, **innovative approaches** to data collection will be needed; these might include online surveys, machine learning or artificial intelligence (e.g, analytics from digital platforms that users visit for information on self-care).
- Resources should be dedicated to collecting **data that are disaggregated** by relevant sociodemographic characteristics to demonstrate whether self-care is affecting equitable access to quality care, and to demonstrate its utility for advancing UHC.
- The expansion of self-care interventions increases the importance of collecting information from the **private sector**—for example, through digitized data collection at points of sale—and of aligning HMIS to collect and integrate data from multiple sources, facility types, and sectors.

It was also recommended that future efforts to support the development and consolidation of self-care metrics include:

- Developing a **compendium of resources** that provide self-care indicators could help stakeholders working to identify metrics on self-care, thereby accelerating progress toward developing a set of standardized indicators. A scoping review of SRH self-care indicators is one approach to inventorying and consolidating tools and resources and indicators. This could be used to assess the quantity of indicators—and perhaps also the strength or quality of the indicators—according to self-care intervention and domain (e.g, awareness, demand, uptake, quality, cost, coverage, outcomes).
- Producing **a guidance** on measurement in self-care interventions, to highlight the principles that should guide indicator development and data collection on these indicators. If resources allow, the guidance could even include a compilation of recommended indicators. The guidance could also delve into the potential of employing innovative approaches to data collection, and strategies for triangulating data from multiple sources.

WHO notes that self-care "recognizes individuals as active agents in managing their own health care, including health promotion; disease prevention and control; self-medication; providing care to dependent persons." The development and utilization of appropriate metrics can help SRH programs identify where investments are needed to help realize these overall goals of self-care.



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RECOMMENDED CITATION

Self-Care Trailblazer's Group. Measurement of Sexual and Reproductive Health Self-Care: Challenges and Opportunities. Population Services International, Washington, DC, June 2022

ANNEX 1. ILLUSTRATIVE SRHR SELF-CARE MEASURES AND INDICATORS

	SRH SELF-CARE INTERVENTION					
	1. Self-managed abortion		**2. Self-administered hormonal contraception**		**3. HIV self-testing**	
Self-Care Measurement Domain	**Measure/Indicator**	**Typical Data Source**	**Measure/Indicator**	**Typical Data Source**	**Measure/Indicator**	**Typical Data Source**
Awareness of self-care options	Source of information about [specific self-managed abortion option, e.g., hotline, telemedicine, or accompaniment program]	PS	Percentage of women of reproductive age who have heard of a type of injectable contraception that you can inject yourself [5]	PBS	Percentage of population aware of HIVST [8]	PBS
Preference for self-managed care options†	Percentage of individuals who prefer each source of medication abortion care, among women who have had at least one medication abortion (e.g., facility, telemedicine, self-managed without clinical support, no preference)	PS, PBS	Percentage of non self-injectable contraceptive users who would consider using it in the future if they were trained in how to do so [5]‡	PBS	Percentage of the population willing to self-test if available [8]‡	PBS
Access to self-care, including cost	Percentage of women seeking an abortion who accessed information on self-managed abortion from a specific source of information (e.g., Internet, family or friends, informal vendors, etc.) [2]	PS, PBS	Average retail price of DMPA-SC [6]	SPA	Number of sites distributing HIVST kits [8]	HMIS
Use (including incidence, prevalence and continuation of use)	Percentage who report using a specific drug regimen (mifepristone and misoprostol in combination, misoprostol only, or other substances or drugs) [1]	Other	Number of DMPA-SC users who choose to self-inject [5,6]	PBS	Number of HIV self-test kits distributed [8]	HMIS
	Gestational age at time of abortion [3]	Other			Percentage of the population who has ever self-tested [8]	PBS

	SRH SELF-CARE INTERVENTION					
	1. Self-managed abortion		**2. Self-administered hormonal contraception**		**3. HIV self-testing**	
Self-Care Measurement Domain	**Measure/Indicator**	**Typical Data Source**	**Measure/Indicator**	**Typical Data Source**	**Measure/Indicator**	**Typical Data Source**
Quality of care and user experience (including acceptability and satisfaction)	Percentage of clients who felt they received quality medications from a reliable source or knew where to obtain them [4]	Other	Percentage of providers who feel confident training individuals in self-injection [5]	SPA	Percentage of HIVST users who were satisfied with their HIVST experience [9]	Other
	Percentage of clients who felt prepared for what to do if they experienced warning signs or in the event of a complication [4]	Other	Proportion of DMPA-SC self-injection users reporting side effects or adverse events [7]	HMIS	Percentage of HIVST users who think that their family or friends would use HIVST [9]	Other
		Other			Percentage of HIVST users who report coercive testing (being "forced to test", typically by a main partner) [9]**	Other
Outcomes and linkages to health systems††	Percentage of users of self-managed abortion who report a complete abortion, with and without surgical intervention [1]§	Other	Proportion of DMPA-SC self-injection users who sought treatment for side effects [7]	HMIS	Percentage of HIVST users with reactive results, confirmed HIV positive [10]††	v
	Percentage who report adverse events (heavy bleeding, extreme pain, foul-smelling discharge, high fever, receipt of antibiotics, receipt of manual vacuum aspiration or dilation and curettage, blood transfusion, receipt of intravenous fluids, or overnight facility stay) [3]	Other			Percentage of HIVST users with confirmed positive results initiated on ART [10]††	v
	Percentage seeking medical care at a health facility during or after their abortion process, and reason for doing so (e.g., to confirm completion of abortion, concern about adverse effects, for surgical intervention, other) [1] ¶	Other			Percentage of index clients accepting HIVST for distribution to their partners [10]	v

	SRH SELF-CARE INTERVENTION					
	1. Self-managed abortion		**2. Self-administered hormonal contraception**		**3. HIV self-testing**	
Self-Care Measurement Domain	**Measure/Indicator**	**Typical Data Source**	**Measure/Indicator**	**Typical Data Source**	**Measure/Indicator**	**Typical Data Source**
Inequities in all the above	Disaggregation by age and education level [3]	Other	Number of DMPA-SC units sold by geographic region [6]	Other	Disaggregation by age group, sex, key population [8] and program approach (e.g., community-based, facility-based, index case, partner) [10]	HMIS

Abbreviations: HMIS = health management information system; SPA = service provision assessments; PS = patient survey; PBS = population-based survey; Various = various other data sources, e.g., national program data, individual research studies

TABLE NOTES

† Indicators that capture values or preferences for self-care over other models are critical for capturing whether self-care is used as a preferred mode of delivery rather than a last resource. For interventions that are legally restricted, indicators may need to reference to hypothetical settings in which multiple modes of delivery other than self-care are available to gauge preferences.

‡ While indicators across several self-care interventions assess willingness or intention to use the self-care option, willingness/intentions to use are distinct from preference to use, and additional indicators that directly assess preferences should be formulated.

§ The primary outcome of interest is successful completion of an abortion, regardless of the use of surgical intervention. This indicator may be disaggregated by whether or not a surgical intervention occurred depending on the specific monitoring or research purpose.

¶ Qualitative evidence and insights from program experience suggest that people may seek facility-based medical care before, during, or after the abortion process for a variety of reasons, including personal preferences in addition to complications. Therefore, health-facility based care seeking during a self-managed abortion process should not be viewed categorically as a negative/adverse outcome or "failure" of the self-managed abortion process.

** Indicators that directly assess unintended consequences of self-care options, including gender-based violence or reproductive coercion, are needed across specific self-care interventions.

†† Measuring linkages to care (such as confirmatory testing upon a reactive HIVST result) is often challenging without endangering users' privacy and autonomy. Alternative approaches to measuring linkages to care and outcomes in the context of HIVST have been proposed by Choko et al. 2020 [11] and should be considered across SRHR self-care interventions.

TABLE CITATIONS

[1] Moseson, H., Jayaweera, R., Raifman, S. et al. Self-managed medication abortion outcomes: results from a prospective pilot study. Reprod Health 17, 164 (2020). https://doi.org/10.1186/s12978-020-01016-4

[2] Moseson H, Herold S, Filippa S, Barr-Walker J, Baum S, Gerdts C. Self-managed abortion: A systematic scoping review. Best Practice & Research Clinical Obstetrics and Gynaecology. 2020;63:87-110. https://doi.org/10.1016/j.bpobgyn.2019.08.002

[3] Moseson H, Jayaweera R, Egwuatu I, Grosso B, Kristianingrum IA, Nmezi S, et al. Effectiveness of self-managed medication abortion with accompaniment support in Argentina and Nigeria (SAFE): a prospective, observational cohort study and non-inferiority analysis with historical controls. Lancet Global Health. 2022;10.1:E105-E113.

[4] Nirali M Chakraborty, Erin Pearson, Caitlin Gerdts, Sarah E Baum, Bill Powell, Dominic Montagu. Toward a standard measure of abortion service quality-a stakeholder first approach. Frontiers in Reproductive Health. 2022. DOI: 10.3389/fgwh.2022.903914.

[5] DMPA-SC Self-Injection Learning Exchange (SI-LX); Director: Erica Sedlander (University of California, San Francisco); Principal Investigators: Kelsey Holt and Jenny Liu (University of California, San Francisco)

[6] DMPA-SC Access Collaborative. Counting on the private sector to under the total market. 2021. https://fpoptions.org/wp-content/uploads/MSIC-S7-private-sector-PATH-JSI-2021.pdf

[7] Kennedy CE, Yeh PT, Gaffield ML, et al. Self-administration of injectable contraception: a systematic review and meta-analysis. BMJ Glob Health. 2019;4:e001350. doi:10.1136/bmjgh-2018-001350 https://gh.bmj.com/content/bmjgh/4/2/e001350.full.pdf

[8] HIV self-testing strategic framework: a guide for planning, introducing and scaling up. Geneva: World Health Organization; 2018. Licence: CC BY-NC-SA 3.0 IGO. https://www.afro.who.int/sites/default/files/2019-12/9789241514859-eng.pdf

[9] Choko AT, MacPherson P, Webb EL. et al. Uptake, accuracy, safety, and linkage into care over two years of promoting annual self-testing for HIV in Blantyre, Malawi: A community-based prospective study. PLoS Med. (2015). https://doi.org/10.1371/journal.pmed.1001873.

[10] Meeting Targets and Maintaining Epidemic Control (EPIC) Project. HIV Self-Testing Operational Guide. 2021. https://www.fhi360.org/sites/default/files/media/documents/epic-hiv-self-testing-guide.pdf

[11] Choko AT, Jamil MS, MacPherson P, et al. Measuring linkage to HIV treatment services following HIV self-testing in low-income settings. JIAS. 2020;23:32548. http://onlinelibrary.wiley.com/doi/10.1002/jia2.25548/full | https://doi.org/10.1002/jia2.25548