# What we know and don't know about adolescent girls and young women and HIV prevention in sub-Saharan Africa

Mapping findings across completed, ongoing and planned projects

Companion analysis to AGYW Project Database



Accelerating Product Introduction Informing Product Development Reducing Time to Impact





### **PURPOSE**

To map the landscape of ongoing, planned and completed work on HIV prevention and adolescent girls and young women (AGYW) in sub-Saharan Africa (SSA) to:

- 1.) Inform collaborations; and
- 2.) Identify gaps and next steps for market research.

This document is the fourth iteration and is updated on a bi-annual basis. Please contact avac@avac.org with updates or additions to the information included in this mapping.

### **OVERVIEW**

Landscape mapping includes ongoing, planned and completed work on AGYW in SSA. Other populations are included when projects also pertain to AGYW. Data sources include: structured interviews with key stakeholders, group meetings with organizations (including pharmaceutical product developers, academic researchers, marketing agencies and program implementers) and a biannual survey of ongoing and planned projects. Key stakeholders and organizations interviewed and projects in mapping include those looking at HIV prevention broadly, with a focus on oral PrEP, but also specific projects with overlapping design, questions, population and geography where findings could be of relevance. Projects will be added to the mapping as they are identified.

The HIV Prevention Market Manager (PMM) Project undertook this mapping and will update the mapping on a bi-annual basis. Through the PMM Project, AVAC and CHAI seek to facilitate an efficient and effective rollout of HIV prevention products. The PMM works with partners across the prevention research-to-rollout spectrum to expand the portfolio of options and ensure appropriate products are available, accessible and used by those who need them most. There is often a delay in moving products from the research and development stage to rollout, uptake and impact. The PMM Project addresses this lag by identifying critical gaps and overlaps, facilitating coordination, compiling and disseminating information and providing strategic technical support. Working with the full range of actors and initiatives, the PMM Project makes clearer where strategic investments in prevention products are needed and supports accelerated introduction, consistent, correct uptake by AGYW and informs future product development.

The main aim of the mapping process was to respond to a request by those interviewed for the PMM Project to document and disseminate the landscape of AGYW work already underway as well as identify gaps in the field. The intent is to share and iterate this report to include additional detail and projects as they begin and as information is available. The report will be disseminated to organizations involved in research on AGYW to start a process of information-sharing and coordination between organizations, as well as to guide development of the PMM-led research and implementation agenda. We do not attempt to assess study quality.

### **PARAMETERS**

Population | Adolescent girls & young women 13-29<sup>1, 2</sup>

Geography | Sub-Saharan Africa

Timeframe | Ongoing (not yet fully complete), planned and completed work<sup>3</sup>

Focus | Projects, studies, and initiatives that include HIV prevention as a parameter or outcome<sup>4</sup>

Timeframe for the mapping includes all projects that are ongoing, planned and completed as of December 2018. Search parameters include previous five years, not excluding ongoing studies that began prior to 2012. Studies that are in the nascent planning stages are not included in full detail and will be included as the review is updated on a bi-annual basis.

Completed projects are included for relevance to the mapping and possible implementation of project outcomes. With such a fast-moving and changing field, completed projects may no longer have direct relevance to inform programmatic outcomes. That said, because this mapping analyzes specific findings gleaned from projects, completed projects are key to the findings contained herein.

Status of projects ongoing and planned varies. For example, some planned projects are seeking ethics review and others are still in early stage development of the protocol.

This area of work is highly dynamic, with a number of new projects being discussed, funded, designed and/or implemented. This landscape map intends to be a living document that can be updated with new initiatives and can, hopefully, be a guide to funders and implementers when considering what is already happening, what gaps might exist and what new work is needed.

<sup>&</sup>lt;sup>1</sup> The work included in this review includes other populations when they are enrolled in projects covering AGYW.

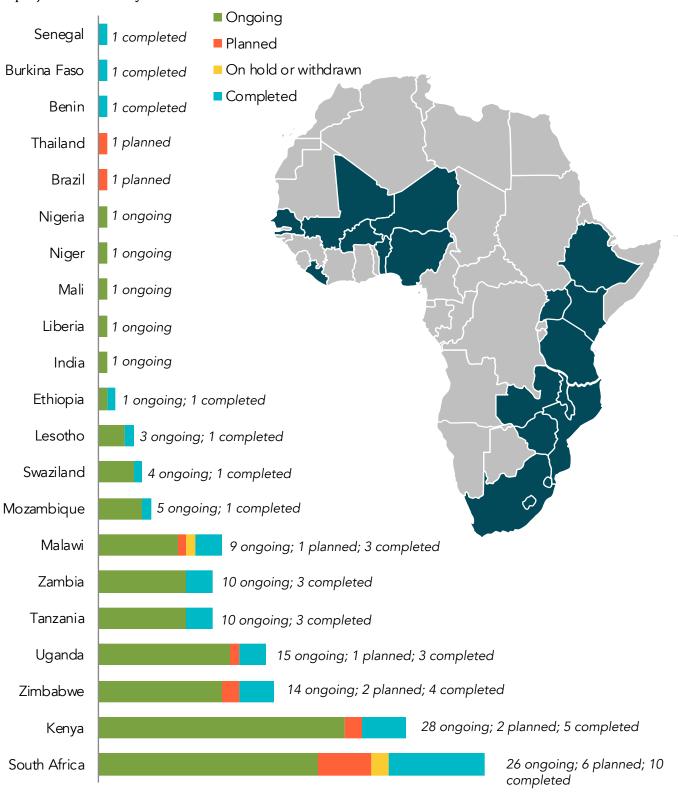
<sup>&</sup>lt;sup>2</sup> The work included in this review expands the age range where relevant or where projects include a wider range.

<sup>&</sup>lt;sup>3</sup> The work included in this review also includes select completed work.

<sup>&</sup>lt;sup>4</sup> Several projects included in this review are of relevance, but do not have an explicit focus on biomedical HIV prevention.

### **OVERVIEW OF PROJECTS**

The Market Manager identified 81 stakeholder organizations working on **120** ongoing, planned and completed projects in 21 countries, across the SSA region and globally. (Findings from only 20 countries were included in this analysis.) A variety of qualitative methods as well as quantitative approaches have been used to capture information from the **90** ongoing, **7** planned and **23** completed projects in the study area.



### INSIGHT ANALYSIS METHODOLOGY

Analysis of final or interim findings from ongoing and completed projects on HIV prevention for AGYW in SSA found **308** unique, relevant findings from **49** projects. Projects with a primary objective other than HIV prevention or findings broadly focused on AGYW well-being were not included.

Individual findings were plotted along the *social ecological model* and *behavior change* framework to pinpoint where each fits in an AGYW's HIV prevention journey. Certain projects were excluded from the analysis if they did not meet inclusion criteria and were unable to be placed along the frameworks. Findings that applied to more than one category within a framework were counted in all to which they belonged.

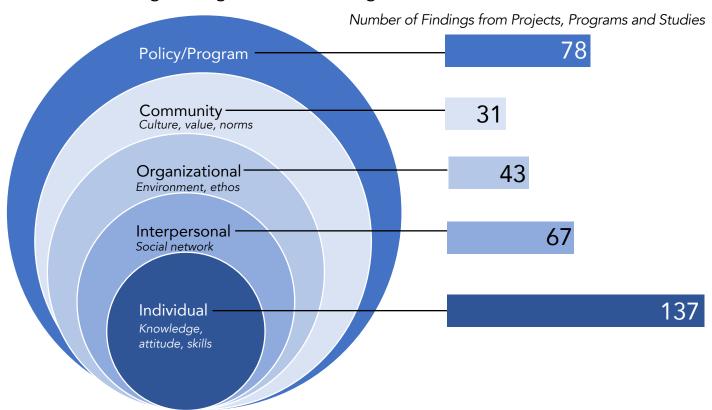
Social Ecological Model	Behavior Change Framework
<b>Individual</b> Knowledge, attitude, skills	Awareness
<b>Interpersonal</b> Social network	Evaluation
<b>Organizational</b> <i>Environment, ethos</i>	Uptake
<b>Community</b> Culture, value, norms	Adherence
Policy/Program	Championing

Findings that contained information on influencers were also analyzed based on type of influencer. Findings were categorized as product-agnostic or product-specific; those that pertained to specific prevention products were analyzed by product type.

Influencers	Products
Male partners	Oral PrEP
Family	Ring
Peers	Long-acting injectable
Health care providers	☐ Implant
Teachers	Condoms
Community leaders & religious figures	Film
Policymakers	Gel
	Family planning

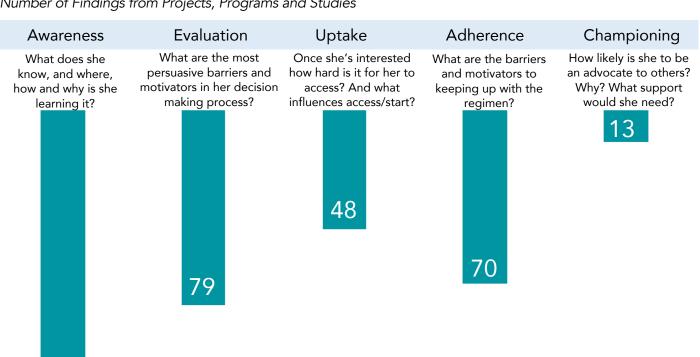
### **ANALYSIS OF PROJECT, STUDY** & PROGRAM FINDINGS

Level of Knowledge Along the Social Ecological Model



### Level of Knowledge Along the Behavior Change Framework

Number of Findings from Projects, Programs and Studies



### What we know: Insights across projects

### INDIVIDUAL

### 137 FINDINGS

AGYW need HIV prevention products designed to fit their lifestyles. They want options.

AGYW have misconceptions about prevention products and need expanded access to accurate information. AGYW are concerned about side effects of prevention products, particularly PrEP.

AGYW have low self-perception of HIV risk, but exhibit risk behaviors, such as inconsistent condom use, no knowledge of partner's HIV status, multiple partners and transactional sex.

**AGYW** have low adherence to prevention products, including PrEP and the dapivirine ring, suggesting a need for additional support to maintain use after uptake.

### PRODUCT INSIGHTS

In general, AGYW and health providers prefer a product that has a longer duration, flexible structure, and helps to reduce clinic visits. AGYW care about product aesthetic; how a product looks can affect their desire to use it. Lack of understanding around reproductive anatomy may deter AGYW from using unfamiliar products such as the vaginal ring, as opposed to pills and injectables. In multiple studies, women preferred injectables. PrEP is less desirable because it requires daily use and AGYW are concerned about stigma, as pills can be conflated with ARVs, and potential and actual side effects.

### **INTERPERSONAL**

### **67 FINDINGS**

The majority of interpersonal insights pertained to male partners, compared to family, peers, providers, teachers, and other influencers.

**Social support** from partners, peers, mentors and family members for HIV prevention is a determinant of both AGYW risk behaviors and product uptake and adherence.

Intimate partner violence negatively affects AGYW product use.

Male partners typically have multiple concurrent relationships with inconsistent condom use. Trust in relationships with male partners motivates AGYW prevention choices, as well as whether they disclose their product use.

Some girls and women prefer to keep their product use private, fearing their partners will disapprove or distrust them, and make decisions based on how effectively they can maintain their privacy.

### **ORGANIZATIONAL**

### 43 FINDINGS

A resounding finding across projects and countries is that health care providers are failing to meet the sexual and reproductive health needs of AGYW. Location of where to obtain HIV information and services for AGYW matters significantly.

AGYW and FSWs often feel that health care providers do not provide a friendly, non-judgmental space to discuss HIV prevention, and sexual health generally, and they will avoid spaces where they feel stigmatized or mistreated.

**Bias against AGYW sexual activity** can skew the information, counseling, and options that providers offer. This has been found to be a barrier to PrEP provision in particular.

Strategic interventions that move beyond traditional health service delivery sites to locations AGYW are likely to frequent have proven effective at reaching them. HIV prevention programs in schools, libraries, and – in the case of FSWs – bars and brothels, as well as mentorship programs, have been successful at mitigating stigma and creating safer spaces for AGYW to access information and services.

### What we know: Insights across projects

**COMMUNITY** 

31 FINDINGS

Cultural norms around gender and sexuality embedded in communities shape the HIV prevention behaviors of AGYW.

Health care providers, community leaders and parents/guardians tend to associate use of HIV prevention products with promiscuity and having HIV, which stigmatizes them. This, in turn, deters AGYW from seeking out HIV prevention information and services, including at health facilities.

There is a clear need for more robust community awareness/sensitization initiatives that are tailored to specific influencers and address their misconceptions, such as clarifying that products like PrEP will not have any effect on sexual behavior or fertility.

Low levels of information on HIV prevention in communities place the onus on AGYW to educate others on prevention products. Communities and partners may not perceive AGYWs as the best messenger. Because of this, it is important that partners and family members have accurate information from trusted sources, such as health care providers, to increase their support of AGYW product use.

### POLICY/PROGRAM

79 FINDINGS

Program and product design and messaging should focus on AGYW empowerment, control, and safety. They should also address concerns around stigma, such as reluctance to interact with the health system and product packaging.

PrEP messaging, for instance, should differ among segments of targeted, high-risk populations.

**Interventions should also correct misinformation**, such as the notion that women do not need to use condoms while taking PrEP.

AGYW respond to HIV prevention messaging that contains self-empowerment themes; they do not necessarily consider themselves at high risk of HIV, and messages that focus too heavily on HIV can be offputting for them. By contrast, community members are concerned that messages focused on AGYW empowerment could encourage sex and promiscuity, and prefer them to focus on protection from HIV.

Interventions should concurrently target influencers in AGYWs' lives as a way to maximize potential success. Influencers can determine the effectiveness of a product or intervention, and programs should provide them with information to temper their concerns and bolster their support of AGYW.

### STRUCTURAL DRIVERS

High mobility and distance from health facilities contributed to low retention and loss to follow-up for AGYW and FSWs.

**Socioeconomic factors**, including cost of products and cost of travel to health facilities, underlie barriers to HIV prevention.

## **Individual findings** from several projects with potential implications for research protocols, programs and policy

### **UPTAKE**

- A study in South Africa found that wanting to be in control and protected is connected to AGYW's
  motivation to take oral PrEP. Oral PrEP use instills a sense of power amid their risk and vulnerability.<sup>5</sup>
- It also found that acknowledging perceived HIV risk is critical to moving AGYW from awareness of oral PrEP to uptake. Programs should tailor messaging to different stages of PrEP use.<sup>6</sup>

### **ADHERENCE**

- In Senegal, a study concluded that providing feedback to patients about their oral PrEP adherence patterns could be the most important adjustable factor to influence adherence.<sup>7</sup>
- In a study in Malawi, South Africa, Uganda, Zimbabwe, participants felt young women's non-adherence to the dapivirine ring was due to being less "serious" about the future and HIV prevention; driven largely by benefits; fears of the potential impact of the ring on their fertility; and to having less control in their relationships.<sup>8</sup>

### **INFLUENCERS**

- In Kenya, a study found male partners to be the determinant in nearly all AGYW's decisions around using oral PrEP.<sup>9</sup>
- A program in Zambia reported that mentors who had favorable attitudes towards contraception, created safe spaces for AGYW, had solid relationships with girls and the community, and had high self-efficacy were linked to positive impacts on AGYW's sexual and reproductive health and lives, including decreased likelihood of unintended pregnancy, unwanted sex, marriage, giving birth, and having HIV.<sup>10</sup>

### **PRODUCT PREFERENCE**

• In Kenya and South Africa, a study concluded that having privacy at home seemed to be the main factor discerning lack of interest from AGYW in the ring compared to the pill. A private room could be necessary for an AGYW to be able to insert or remove the ring, while taking a pill can be done in any location.<sup>11</sup>

### **IEC MATERIALS**

 In a South Africa-based study, printed materials legitimized oral PrEP for AGYW's partners and families, who at first expressed skepticism at a pill that prevents HIV.<sup>12</sup>

### **SERVICE DELIVERY**

• A study in Kenya and Uganda highlighted that in rural settings, adolescent girls have low rates of school and health clinic attendance, so health service delivery sites that are located outside of schools and health facilities may be ideal for linking a diverse group of adolescents to HIV prevention.<sup>13</sup>

<sup>&</sup>lt;sup>5</sup> Shannon O'Rourke, Laura Myers, Connie L. Celum et al., 3Ps for Prevention Study (PrEP, Power, Pride), 2018.

<sup>&</sup>lt;sup>7</sup> Eric Tousset, Souleymane Mboup, Daouda Gueye et al., Senegal PrEP Demonstration Project, 2018.

<sup>&</sup>lt;sup>8</sup> ET Montgomery, J Stadler, S Naidoo et al., MTN-032/AHA Study, 2018. <sup>9</sup> Sarah Roberts, Targeted interventions to address the multi-level effects of gender-based violence on PrEP uptake and adherence among adolescent girls and young women in Kenya (Tu' Washindi na PrEP), 2018.

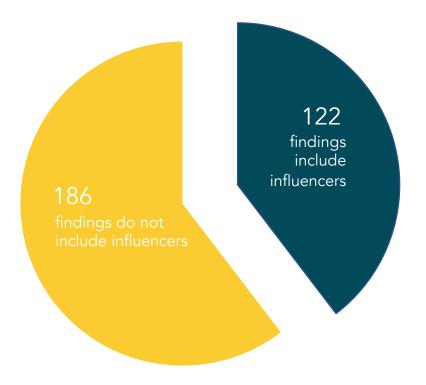
<sup>&</sup>lt;sup>10</sup> Karen Austrian, Paul C. Hewett et al., Adolescent Girls Empowerment Programme, 2016.

<sup>&</sup>lt;sup>11</sup> Ariane van der Straten, Kawango Agot, Khatija Ahmed et al., The Tablets, Ring, Injections as Options (TRIO) Study, 2018.

<sup>12</sup> L. Myers, L.-G. Bekker, R. Aunger et al., 3Ps for Prevention Study, 2018.

<sup>13</sup> Kevin Kadede, Theodore Ruel, Jane Kabami et al., The Sustainable East Africa Research in Community Health (SEARCH) Study, 2017.

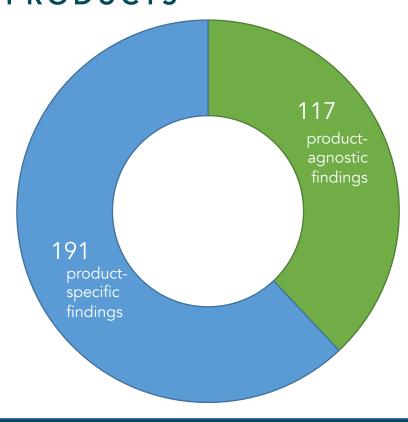
### FINDINGS ON INFLUENCERS



40% of findings from projects in sub-Saharan Africa contain information on influencers

# TYPES OF INFLUENCERS IN FINDINGS 3%2%2% Male partners Providers Peers Family Community leaders/religious figures Teachers Policymakers

# FINDINGS ON HIV PREVENTION PRODUCTS



62% of findings from projects in sub-Saharan Africa concern specific HIV prevention products.

Of these, 77% pertain to pre-exposure prophylaxis (PrEP).

# TYPES OF PRODUCTS FOUND IN FINDINGS

