



# #WhatWomenWant HIV prevention that works for adolescent girls and young women

Adolescent girls and young women (AGYW) put HIV prevention on the Fast-Track by leveraging social media and young women-led movements

Involve and consult AGYW in every stage of policy and programming and provide leadership roles Promote universal access to Implement laws, complete and comprehensive policies, and services information, and youth-friendly, that address gendernon-judgmental, confidential, based violence (GBV) and accessible services against AGYW Condoms STRUCTURAL INTERVENTIONS Pre-exposure prophylaxis (PrEP) Involve us for HIV prevention that works **HIV** testing services, antiretroviral therapy, Social and voluntary medical programmes for men SETANOLRIAL INTERVENTIONS School-based Keeping girls in school prevention (in context of comprehensive Multimedia and new media Community mobilization Address the needs of Provide adequate, AGYW from all groups sustainable funding for and ensure access to initiatives for and by services and information women and AGYW

# Why #WhatWomenWant works

## Using new social media and digital platforms:

- enables significant participation in terms of numbers, diversity, and geographical reach
- democratizes participation and creates new pathways for young and upcoming advocates to participate
- provides a platform for AGYW to raise their questions, talk about what matters to them, and present their concerns to decision-makers
- generates significant quantity and quality of research data with limited time and resources
- builds spaces and opportunities for AGYW to engage with decisionmakers and key stakeholders using platforms they are comfortable with in an informal setting
- represents a new platform for conducting research using WhatsApp as an innovative research and engagement tool
- generates a space for AGYW to engage with peers from other countries and contexts, creating a shared, safe community space
- 8 presents alternative routes to engage with guidelines and policies
- harnesses AGYW's voices and advocacy, amplifying their voices and agency.

# #WhatWomenWant - HIV prevention that works for adolescent girls and young women

HIV disproportionately affects adolescent girls and young women (AGYW). Harmful gender norms and social expectations, unequal access to education and information, limited agency, and systematic rights violations contribute to this reality, and have limited the success of HIV prevention for and with AGYW to date.

Addressing this disproportionate burden is increasingly prioritized in the global HIV response. Achieving an end to HIV as a public health emergency can only be realized if everyone – the most marginalized, the most affected, the most disenfranchised – are reached with the knowledge and tools to prevent HIV transmission, and have the power and agency to use them effectively. There are many barriers to achieving this for adolescent girls and young women, yet there are also significant opportunities – now is the moment to turn the tide.

Achieving this takes more than strategies and commodities. Both are essential, as are meaningful resources and political will. But, truly transformational change critically depends on developing the leadership, platforming the voices, and realizing the knowledge and solutions of adolescent girls and young women themselves.

"It's time to be inclusive, innovative, and entertaining about SRH and HIV prevention techniques. With the age of technology and other 21st century developments, we cannot continue using an old yardstick to spread SRH and HIV prevention message. The only way to reach the adolescent and youth population is to talk like the youth, interact and be creative."

KGOMOTSO MOAGAESI, #WHATWOMENWANT WORKING GROUP, BOTSWANA

#WhatWomenWant is a global movement, led by ATHENA that seeks to promote this very simple principle: that the most affected are the most informed, and real solutions come from lived realities. #WhatWomenWant is a vehicle to advance gender equality within and outside of the HIV response. Through it, ATHENA seeks to amplify women's voices, highlight our realities, and power our solutions by creating a platform for women, including young women, to influence global policy discourse that doesn't require an invitation, or a visa.

AGYW experience approximately 8,600 new HIV infections each week

Of all women (aged 15 years and older) living with HIV globally, 15% are 15–24 years old

Sub-Saharan Africa experiences a particularly high burden of HIV – it is home to 80% of the world's AGYW living with HIV

AGYW in sub-Saharan Africa are twice as likely to be living with HIV than their male peers

Women acquire HIV at least **5–7 years earlier than men** in sub-Saharan Africa

We dernand prevention that works



UNAIDS 2016 Guidance: HIV prevention among adolescent girls and young women; UNAIDS Gap Report 2016

#WhatWomenWant is powered by young women who want to be meaningfully involved in making change for women and girls. The campaign operates through the engagement of an expansive network of primarily women-led organizations and individuals working to advance women's rights and health, to identify and communicate key advocacy opportunities. It creates opportunities to access information, share experiences, propose solutions, and advocate for change, that are open, accessible, and work effectively within the lives of AGYW themselves, using the tools and media with which they are already engaged.

Delivering effective HIV prevention programmes for AGYW and achieving the ambitious target to reduce HIV acquisition amongst them to fewer than 100,000 by 2020 (as set forth in the 2016 UN Political Declaration on Ending AIDS) requires that these very girls and young women are meaningful partners in the effort bringing their needs, priorities, visions, and solutions forward.

We brought these principles of leadership and meaningful involvement, through new social media and innovative methods, to this project, which aimed to move the new UNAIDS guidance on HIV prevention among AGYW off the page and into action.

The guidance, HIV prevention among adolescent girls and young women: Putting HIV prevention among adolescent girls and young women on the Fast-Track and engaging men and boys was published in late 2016, and is intended to act as a conceptual framework to guide effective design, implementation, and delivery of HIV prevention programmes for AGYW. To do this effectively, ATHENA believes it must be implemented in an informed, contextual approach that takes into account the specific needs, rights, experiences, and challenges of the AGYW it aims to serve. We therefore carried out, with UNAIDS support, a consultation amongst AGYW, to respond to the guidance.

"Policy-makers have always been able to know what women 'Need', but now it is time for us to speak out openly about 'What Women Want."

ANNAH SANGO, #WHATWOMENWANT WORKING GROUP, ZIMBABWE

We engaged AGYW in reflecting, taking ownership, and using the strategies outlined in the guidance, engaging directly with implementers and decision-makers to identify barriers and challenges, and articulate solutions that are rooted in their lived experience, professional knowledge, and community understanding.

We asked AGYW what they needed for and from the guidance, to best enable it to deliver on its aim to reduce HIV incidence among AGYW. By utilizing a range of innovative methods to consult, inform, and amplify the voices of AGYW, we empowered adolescent girls and young women with the knowledge of this guidance and engaged them as advocates for it and their HIV prevention priorities.

Much of the attention to date toward adolescent girls and young women in the context of HIV has focused on them as recipients of services and targets of interventions. We have the opportunity to strengthen and amplify these efforts by engaging adolescent girls and young women as change agents, leaders, and partners who demand what works to protect themselves from HIV, realize their dreams,

and to thrive.

Engage us in HIV prevention guidance



The **#WhatWomenWant campaign** originates from organizing by the Women's Major Group during the Post-2015 Sustainable Development Goals intergovernmental negotiations to influence policy that

advances women and girls' rights and leadership.

#WhatWomenWant was re-galvanized at the 60th Commission on the Status of Women, when activists united to call for change, to ensure that governments are held accountable to international agreements and commitments set. It is a vehicle to bridge women into policies, practices, and interventions to improve our lives.



"Meaningfully involve adolescent girls and young women in all their diversity in the policy processes, that is, formulation, implementation, dissemination, and evaluation for sustainable actions and results. We are able and ready!" KENYA



#### **REACHING AGYW IN ALL THEIR DIVERSITY**

Adolescent girls and young women affected by HIV are a vast, diverse group of individuals. Our aim was to reach AGYW and involve them in an inclusive process using multiple methods to inform, consult, and advocate. Reaching AGYW in their diversity was a core goal of this project, and one which we achieved by developing a multi-pronged methodology, utilizing existing tools, and new approaches to reach a diverse range of participants.

The methodology included an extended focus group discussion conducted using WhatsApp, a working group, informational webinar, bringing policy-makers into direct dialogue with AGYW through social media, and advocacy through Twitter and other social media. Each arm of the project explored the reach and utility of different tools, allowing us to achieve multiple distinct but mutually supportive aims:

- To operationalize key elements of the UNAIDS guidance namely:
  - Enhanced leadership
  - Multimedia and new media
  - Community mobilization
- 2. To inform AGYW about the UNAIDS guidance and HIV prevention strategies
- To consult AGYW about their values, preferences, and experiences of HIV prevention, including barriers and enablers to the success of different strategies
- 4. To engage AGYW in direct accountability mechanisms with policy- and decision-makers
- 5. To influence HIV prevention for AGYW through creating spaces and platforms for AGYW to advocate for their priorities
- To explore different methods, and their accessibility and utility in engaging AGYW, and innovate new strategies to improve this

A key finding in relation to the methods used in this project, is the potential of WhatsApp as a research and engagement tool. We had not anticipated at the outset how successful this tool would be in engaging AGYW and generating meaningful qualitative data. We conclude that WhatsApp offers significant opportunities for consultation and accountability that are not yet fully explored or realized.

By using and adapting tools that AGYW already use, where they feel comfortable and understand the technical platform of engagement, we found we could create a safe, supportive, and active research encounter. This mimicked many of the elements expected of faceto-face qualitative research but with significantly less restrictions in terms of the numbers of participants, time, and resources required to participate. In addition, WhatsApp contrasts with other more commonly used tools, such as webinars, in that it uses very little data and requires no Wi-Fi access or programme downloads, so is more accessible to a wider range of AGYW. Our use of WhatsApp builds on our past work of creating groups for participants at events such as conferences, but demonstrates the potential to build from practical discussions to research.

The consultation we led focused on three priority countries, Kenya, Zimbabwe, and Malawi, and also engaged AGYW from across eastern and southern Africa.

Our overarching goal was to support AGYW to identify and define their specific HIV prevention priorities, visions, and solutions. Their responses are intended to localise, amplify, and apply the UNAIDS guidance and beyond – into targeted advocacy efforts to inform programmes, reach decision-makers, and mobilize communities in order to implement policy change and increase access to services.

"Media approaches can be more effective if they are widespread geographically and use language that is familiar to the audience or target group." BOTSWANA "Involve communication or social media platforms that reach all people especially those in rural areas that don't get this information."

UGANDA

#### **METHODS AND PARTICIPANTS**

WhatsApp Focus Group: WhatsApp is a free, easy to access and use tool for instant messaging that supports group chats, is end-to-end encrypted, and works using Wi-Fi or cellular data. We knew from previous projects that it is widely used by and accessible to young people, and the #WhatWomenWant working group confirmed it would be an effective tool to reach and engage AGYW.

ATHENA set up a WhatsApp group, titled 'What Women Want Focus Group', and invited AGYW to join. These invites went out through existing WhatsApp organizing groups and other virtual platforms and list-servs, including the WILD Zim virtual group, Civic Leadership Track, YWLI @ Durban AIDS 2016 virtual group, and ATHENA. Additionally, the working group were asked to identify and invite AGYW in their networks, as well as to participate themselves. The focus group was moderated by an ATHENA team member, who also managed adding participants to the group once they had contacted her with a request to participate.

Recruitment information highlighted that the focus group was open to all AGYW interested in issues of HIV prevention, regardless of advocacy or professional experience or education, ensuring that diverse representation.

As of 7 March 2017, when the focus group had been running for a few weeks, there were 185 members participating, with a small drop-off rate of 10–12 who had been participating and then left the group. AGYW participating in the focus group were from at least eight different countries: Botswana, Kenya, Malawi, Namibia, South Africa, Swaziland, Uganda, and Zimbabwe.

The group moderator welcomed participants and outlined the purpose of participating, at regular repeated intervals as new participants joined. Very few off-topic posts were shared, and when this happened the moderator identified them and reminded the participant to stay on topic. The focus group adopted a semi-structured approach, with topics introduced and a set of key questions asked, generally pertaining to experiences, access and barriers or successes. The group opened with a general question around barriers, and later moved to a structure, based on exploring the

key HIV prevention strategies highlighted in the UNAIDS guidance. The moderator shared, as an image, the page from the ATHENA summary of the guidance for the strategy to be considered, and then asked a number of questions. Participants were invited to respond to these questions and identify their country in their first response, to enable a country analysis. As of 19 March, the focus group had elicited 460 meaningful responses. Meaningful being defined as substantive replies to questions, excluding short messages of support or disagreement that did not introduce new content.

There were variations in participation rates, with some participants highly active. However, the nature of the WhatsApp group as the research encounter enabled ease of access for participation, and allowed participants to respond at times that were convenient to them, and to respond at the same time as others without disrupting the research process. For example, Question 2 elicited 17 substantive responses from participants from 5 different countries, and Question 3 received 17 responses from 6 different countries.

The extent of participation was significant, and far greater than anticipated. Each question elicited many substantive responses and discussions, and the group was continually active throughout the period it was open. The detail, depth of knowledge, and range of experience and expertise demonstrated in the responses – and visible in the findings, which make up the bulk of this issue brief – was testament to the extraordinary untapped resource of knowledge, skills, and leadership amongst AGYW and made clear the potential of AGYW themselves to define and implement the change needed to enable effective HIV prevention that really works in the real lives of AGYW.

As a methodology, the WhatsApp focus group lacked the benefits associated with face-to-face research, such as the ability for the researcher to see body language, and for a group dynamic to emerge in the room. However, it was notable that a strong group dynamic did emerge, with a great deal of interaction, debate, and support. This likely reflects the participants' ease and experience of interacting online, and the shift from a binary distinction between online and 'in real life' communication to more fluid shifts between the two. Contributing in writing, as almost all responses were (a few shared short voice recorded messages, another functionality offered by WhatsApp) did reduce the spontaneity of spoken data, but allowed participants time to consider, reflect on, and edit their contributions. As the research topic was formal HIV prevention strategies, and participants were drawing on

Use platforms we can access

professional, personal, and community knowledge and experiences, the written input method was appropriate. Although, the language and literacy requirements this placed on participation was a limitation of the method.

The focus group findings were analyzed thematically using a framework process. All contributions were extracted from WhatsApp and copied into Excel, and there sorted to pull out substantive contributions. These were then sifted and organized by question into a thematic framework, organized by both theme and country of contributor. Data was summarized and exemplar quotes and vignettes retained verbatim. This analysis was conducted by one team member and cross-checked by a second to look for resonance and alignment. Subsequently, the thematic analysis was written up, by strategy area, highlighting the key themes, and retaining the language and substance of the AGYW participants.

Working group: we convened a regional working group of young women leaders from eastern and southern Africa to guide the work, along with institutional partners from the region, and technical support and coordination from ATHENA. The aim of this group was to both provide guidance to the project overall, and to specifically contribute their expertise and insights on considering what should be prioritized in the UNAIDS guidance and its implementation. Members of the working group were nominated by ATHENA team members, institutional partners in Kenya and Zimbabwe, and self-nominations elicited from networks, list-servs, and virtual platforms (as described for the WhatsApp focus group recruitment).

Online and social media: in addition, we utilized social media for Twitter chats and targeted advocacy campaigns. Working group members developed blogs focused on their priority issues, which supported the external reach of the #WhatWomenWant process. More detail on this is outlined in the relevant sections.

Introduction to the Global Fund webinar: one aim of the project was to improve knowledge of and access to decision- and policy-making bodies and influencers amongst AGYW. To support this, we convened a webinar in partnership with Women4GF, during which a presentation about the Global Fund to Fight AIDS, Tuberculosis and Malaria was given and AGYW participating given the opportunity to ask questions. Only 9 AGYW participated, which was relatively low, and we encountered a number of challenges in the process. We used an online webinar tool (GoToMeeting), which like all webinar tools require participants to download

an app or software and have relatively good and stable internet access. Both caused barriers to participation, and we were made aware of a number of AGYW who did not participate either because they could not download the package required or could not access the internet. Webinars

are a very common tool for information-

sharing, capacity-building, and discussion in the HIV movement, and our experiences highlighted a known challenge that we suggest should be considered more fully when selecting tools and methods. We brought the Q&A session in real time to the WhatsApp platform and were able to catalyze a significantly larger audience and greater engagement than through the formal webinar platform.



Virtual dialogue with UNAIDS Zimbabwe: 56 AGYW participated in a virtual dialogue with UNAIDS Zimbabwe using a WhatsApp group created for that purpose. Staff members from UNAIDS Zimbabwe participated, providing updates on current and upcoming activities and priorities, and AGYW were invited to comment and feedback on these, ask questions, and make recommendations. This direct engagement with decision-makers was a key arm of the project in ensuring that AGYW were able to directly influence the implementation of HIV prevention. 55 AGYW continued to engage in an ongoing discussion on HIV prevention for AGYW in the Zimbabwe WhatsApp group.

# UNAIDS HIV prevention guidance for adolescent girls and young women

The UNAIDS guidance, HIV prevention among adolescent girls and young women: Putting HIV prevention among adolescent girls and young women on the Fast-Track and engaging men and boys, was created to inform HIV prevention programmes that aim to reduce acquisition of HIV among AGYW in high incidence settings. The main aim is to consolidate guidance to specifically support countries developing effective HIV prevention programme packages for AGYW. The intended audience of the guidance include policy-makers, planners, and implementers of HIV prevention programmes across sectors. Furthermore, the document is useful for experts in the wider health and social sector programmes, including healthcare workers and teaching staff.

It is not a technical guidance, rather provides concepts and examples on how to do the following:

- Understand the HIV situation of AGYW in the country context
- Design effective responses for AGYW
- Deliver programmes for AGYW
- Measure and sustain programme impacts for AGYW

The guidance presents a programmatic framework and a 'menu of options' or strategy mix for effective prevention programming for AGYW. The strategies aim to address the behavioural, biological, and structural factors driving HIV acquisition, resulting in increased prevention and long-term impact.



HIV prevention among adolescent girls and young women: putting HIV prevention among adolescent girls and young women on the Fast-Track and engaging men and boys

www.unaids.org/sites/default/ files/media\_asset/UNAIDS\_HIV\_ prevention\_among\_adolescent\_ girls\_and\_young\_women.pdf The strategy mix includes:

- 1. condoms
- social and behavioural change communication programmes
- **3.** school-based prevention (in context of comprehensive sexuality education)
- **4.** pre-exposure prophylaxis (PrEP)
- **5.** HIV testing services, antiretroviral therapy (ART), voluntary medical male circumcision (VMMC), and communications for men
- 6. community mobilization
- 7. multimedia and new media
- 8. cash transfers/incentives
- 9. keeping girls in school
- 10. policy and legal change
- **11.** integration with gender-based violence prevention and sexual and reproductive health and rights
- 12. enhanced leadership.

The full guidance is an 80 page document. To facilitate engagement and make it more end-user 'friendly', we prepared a 14 page summary, drawing out the key content for the above 12 core strategies using the language of the guidance but in a simplified structure.

The summary set out the strategy involved, the priority populations, intended effects and settings for delivery, varying slightly depending on the most important content to share for each strategy. The 12 strategies were then shared, one at a time and with targeted questions, to the WhatsApp focus group participants for information and feedback on what would make these strategies work in real life.

## Working group

To provide guidance and leadership to the project, we convened a working group of young women with significant experience of advocacy and leadership on HIV, sexual and reproductive health and rights (SRHR), and gender equality. Twelve young women were identified through a process of outreach, recommendation, and expressions of interest and selected based on their knowledge, expertise, and advocacy experience. The 12 members were from Botswana, Kenya, Malawi, Namibia, South Africa, Uganda, and Zimbabwe. Their interests and background were diverse, bringing a depth and breadth of expertise to support the wider consultation.

In practice, the time working group members were able to devote to engaging with the #WhatWomenWant process was limited, often due to competing engagements and responsibilities. As experienced and

skilled advocates, there are many demands on their time, resulting in a heavy workload. This highlights the urgent need to mentor and support more AGYW to engage in advocacy and develop their skills and experience, to ensure that AGYW are heard effectively in every space and at every decision-making table that affects them, without overloading and risking burnout for the experienced few.

We are hugely grateful for the inputs and valuable insights of the working group members, both through the WhatsApp focus group as well as their working group engagement. In addition, some members blogged about their priority issues, to highlight experiences or challenges that they felt deserved greater focus and attention. These blogs are available to read at <a href="http://whatwomenwant.format.com/feministblog">http://whatwomenwant.format.com/feministblog</a>.

## #WHATWOMENWANT LEADERSHIP IN ACTION



Extract from blog by working group member, **Nyasha Museruka**, **26**, **Zimbabwe** 

As AGYW with disability there is a lot of barriers to HIV prevention among us. One of them is that people don't know about disability ... sometimes people assume he/ she is mentally challenged as well. At some point I visited a clinic and inquired for STI screening services and the nurses there looked at me in astonishment and thought I might have been mentally disturbed to ask for those services since am disabled.

This brings me to my next barrierthere are misconceptions around disability and this has caused a hindrance in us AGYW with disabilities getting services which address our needs as well. People, some policy-makers and even service providers think that we are asexual or we don't get into relationships at all.

There are no policies to protect our rights of getting SRH and HIV services. We have the United Nations Convention on the Rights of people with disabilities (PWDs) (UNCRDP) which has not been adopted here in Zimbabwe. So you cannot sue anyone if there are no policies that talk of our rights as PWDs. The country's constitution does not state clearly on health aspects specifically for PWDs so if AGYW with disabilities don't get the services no-one is to be held accountable.

There is the barrier of communication as well. Service providers like the police officers, teachers, nurses and doctors are not well conversant with sign language or even how to handle clients with Visual impairment.

No materials with information catering for this specific group especially IEC materials. Implementers will always complain that making these materials is costly and sometimes it's a matter of ignorance to their part. AGYW with disabilities are abused sexually due to that language barrier the cases just dies a natural death.

Infrastructure in Zimbabwe is not accessible to PWDs especially where we want to get the services. I wonder why the government approve such plans to be built where wheelchairs users cannot access. You can find a testing service centre located on the 2nd floor and there are no lifts there. It means that person is going back without being helped.

I strongly feel that if these barriers are addressed HIV prevention will also target AGYW with disabilities. People and policy-makers should know that it is vital to programme for us too as we have among us those who are infected too as we are also sexually active.

Stizma and stereotyping are barriers to us accessing HIV prevention

## Focus group findings

As outlined in the methods section, around 185 adolescent girls and young women participated in a focus group conducted on WhatsApp, sharing their experiences, knowledge, and priorities on various aspects of HIV prevention, and barriers and solutions for effective implementation. The findings of that focus group are presented here, by topic area, aligning with the UNAIDS guidance strategies.

WHICH HIV PREVENTION INTERVENTIONS ARE MOST EFFECTIVE IN REACHING ADOLESCENT GIRLS AND YOUNG WOMEN IN YOUR COUNTRY?



#### BEHAVIORAL

1. SOCIAL/BEHAVIORAL CHANGE COMMUNICATION PROGRAMS

2. SCHOOL-BASED HIV

3. COMMUNITY MOBILIZATION

4. MULTIMEDIA/NEW MEDIA

5. CASH TRANSFERS AND SOCIAL GRANTS

6. KEEPING GIRLS IN SCHOOL

#### BIOLOGICAL

7. CONDOM Promotion and Distribution

8. PRE-EXPOSURE Prophylaxis (PREP)

9. HIV TESTING SERVICES (HTS), ANTIRETROVIRAL THERAPY CART), VOLUNTARY MEDICAL MALE CIRCUMCISION

#### STRUCTURAL

10. POLICY CHANGE AND PROGRAMS: GENDER-BASED VIOLENCE (GBV), CHILD MARRIAGE, KEY POPULATIONS, HOUSING, LAND, SEXUAL AND REPRODUCTIVE HEALTH AND RIGHTS (SRHR)

11. INTEGRATION OF GENDER-BASED VIOLENCE PREVENTION AND SRHR PROGRAMS

12. ENHANCING LEADERSHIP AND ROLE MODELS

13. REMOVING LEGAL BARRIERS TO USE OF HIV AND SRH SERVICES

14. YOUTH FRIENDLY SERVICES IN HEALTH FACILITIES

15. FRAMEWORKS FOR PROGRAM DELIVERY AND ACCOUNTABILITY FOR RESULTS

# CHALLENGES IN ACCESSING HIV PREVENTION SERVICES

To open discussion and to begin to assess the HIV prevention landscape through young women's experiences, participants were asked to identify the top challenges adolescent girls and young women face in accessing HIV prevention services.

Many highlighted problems with the **health system** and services, particularly in a lack of youth-friendly services, including failure to operate friendly hours and judgmental and stigmatizing staff. Structural barriers to access were also highlighted, as were the problems caused by failure to uphold privacy and confidentiality. One participant from Zimbabwe highlighted corruption as a particular challenge, and the associated barrier of AGYW being unable to afford the fees required to access services in clinics and hospitals.

"The ease of a young person to access SRH services in different areas of the country that best suits them is quite hard and exposes young people more to vulnerabilities of contracting HIV." MALAWI

Problems with **healthcare staff** were particularly highlighted, including provider attitudes to young people having sex in general and to stigmatizing attitudes towards young people from specific groups:



"Nurses have negative attitudes especially to people with disability." MALAWI

Some participants pointed to a lack of training in providing youth-friendly services for healthcare professionals, while others suggested the challenge was "overwhelmed and overworked" staff. Stereotypes around young people's sexual behaviour, belief that young people should be abstinent, discrimination and stigma around HIV and towards young people living with HIV, and lack of professionalism and expertise were all identified as challenges.

**Stigma** was also identified as a major barrier, including stigmatizing beliefs that AGYW should not be having sex, which prevented them from accessing services. The social construction of AGYW as either people who



"While focusing on the UNAIDS 2016 guidance on HIV prevention on the #whatwomenwant working group, male involvement (changing the norms around masculinity must start from the communities), peer

to peer messaging and meaningful involvement of girls especially on leadership boards and service provision create full ownership for programmes there by supporting the dedication towards a meaningful healthy society."

KYENDIKUWA ALLEN, WORKING GROUP MEMBER, UGANDA

should not be having sex, or who in doing so engaged in risky behaviour, was highlighted:



"Seen as reckless seekers and carriers of disease."
SOUTH AFRICA



"The narrative and autonomy of these young women is not an important factor." SOUTH AFRICA



"Policing and problematization of young people, particularly young women, as sexual beings."
SOUTH AFRICA

Participants suggested that fear of stigma from peers and communities prevented AGYW from accessing services and commodities, and from testing for and seeking information about HIV. In addition, one participant suggested that a belief that treatment of those with medical conditions was more important than investing in prevention, created barriers to service provision.

In particular, stigma against AGYW living with HIV, in schools, healthcare facilities and their communities, was seen as a barrier to disclosure to partners and families, and to service access.

Stigma around condoms was also seen as a challenge, with some suggesting AGYW would see condoms as the responsibility of the male partner, or fear accessing or using them: "[young women] were afraid to learn how condoms are used or getting them." UGANDA

AGYW accessing condoms, or contraception or sexual health services, was taboo, and elicited judgments of 'promiscuity' and stigmatizing treatment.

This links closely with wider challenges generated by **social norms**. Participants suggested that parents do not discuss sexual and reproductive health with their daughters, and that such discussions are also taboo in the community. This limitation on open dialogue, and wider patriarchal structures, means that AGYW are not empowered or informed to make decisions around their own sexual and reproductive health.



"A girl must ask permission to go seek any service from the male head of house." UGANDA

Contributors suggested that men held the greater power in decision-making, limiting the agency of AGYW. Social attitudes towards menstruation were also highlighted, with participants suggesting it was seen as unclean and embarrassing. Social pressures are placed on AGYW around their sexualities and sexual behaviours: "Always told to abstain/keep ourselves pure." SOUTH AFRICA

Conservative cultural and social attitudes limit access to and acceptability of sex education. One participant pointed to a lack of understanding that adolescent girls and young women are a: "peculiar group who are still discovering themselves sexually and they need all the information they can get... from both their parents and healthcare providers in the community." BOTSWANA

Education was also seen as a major barrier, including: information delivered in language that is not understandable or accessible to AGYW; perpetuation of myths and misinformation about HIV; lack of information, especially in rural areas; lack of ageappropriate messaging for AGYW; and information being provided in settings and media that AGYW do not access, such as newspapers and formal meetings: "Find them in their comfort zone and they will pay attention." MALAWI

Poor quality or non-existent sex and relationship education was particularly strongly suggested as a major barrier. Negative and inappropriate messaging in sex education and information was also highlighted:



"Women are not able to engage with the material because it does not relate to their lived experience." SOUTH AFRICA

Access to information, services, or commodities, emerged strongly as a significant barrier to effective HIV prevention for AGYW. Access challenges identified by participants included: poor access to services in rural areas; inadequate or inappropriately delivered information; age of consent barriers; practical barriers to uptake of HIV self-testing including a lack of counselling and safe places to test; stock outs of commodities and supplies in clinics; lack of awareness of available services amongst AGYW; challenges faced by AGYW with disabilities in accessing accurate information and care; and access to sanitary products.

Participants suggested that **policies** could also be a barrier, including interventions that are not evidence-informed and inadequate sex- and age-disaggregated data for programme planning. Age of consent laws were also highlighted as limiting access to contraceptives and HIV testing. Duplication of efforts and bottlenecks were also identified, meaning in some cases AGYW were not reached: "Lack of harmonization from top to bottom." MALAWI

Uneven implementation was also described, with participants suggesting that in some cases good policies were in place but were not implemented in practice.

Other issues highlighted included **harmful cultural practices** such as female genital mutilation and gender-based violence, and poverty.

#### Prep - Access, uptake, and challenges

Participants were asked about pre-exposure prophylaxis (PrEP) in two questions, one general and a second responding specifically to the UNAIDS guidance around PrEP. Responses are amalgamated in this analysis. Questions included whether PrEP was available in their country, if adolescent girls and young women were able to access it, if education was provided, and perceived barriers.

Only a small number of participants reported knowledge about availability of PrEP in their country. It became apparent there was confusion between PrEP, preexposure prophylaxis, and PEP, post-exposure prophylaxis. Participants often made reference to PEP programmes and implementation instead of PrEP. One participant from Malawi had never heard of PrEP and was concerned that it would promote higher risk sexual activity. The lack of knowledge about PrEP contrasted significantly with the high knowledge level demonstrated in regard to other prevention tools and strategies, perhaps due to PrEP being relatively new and not yet widely implemented. Many of the participants were not familiar with PrEP and so responded with first reactions to the explanation provided by the moderator. The confusion with PEP was widespread, and suggests one key area of information strategies to address, not just in understanding what PEP and PrEP are but the relative risks, benefits, and efficacy of each. Some participants felt that PEP would be safer and therefore preferable to PrEP as a short-term measure, with limited insight into efficacy and side-effect profiles.

Participants suggested that **fear of stigma** would prevent AGYW from accessing PrEP, creating an unsupportive environment.

"We're scared to seek services because if you want contraception, condoms or other prevention services like PrEP, one gets judged because then they know you are having sex." SOUTH AFRICA

Among some of the respondents, acceptability of PrEP was an issue.



Fear of developing resistance to antiretrovirals (ARVs) emerged as a barrier to acceptability of PrEP among AGYW. One participant stated: "Personally I would advocate for PEP and not PrEP because the threat of resistance is really huge. So if we are looking at it as a preventative measure, I don't think it's a good one and should only be used where there is no alternative." UGANDA

We need better information on

frEf

One participant also voiced concern about committing to continuous daily therapy: "I'm uncomfortable with the thought of taking a pill (which are ARV drugs) every day. Especially because of the side effects." RWANDA

Access to PrEP was unclear to the participants. Furthermore, accessibility of the drug to all those who may benefit was raised as a concern. Many participants understood that PrEP was available only to specific populations such as female sex workers and others at higher risk of HIV acquisition.

**Lack of education and information** was identified as a major challenge with PrEP. Participants suggested that information was targeted at key populations such as female sex workers but did not take into consideration the general population of young people.

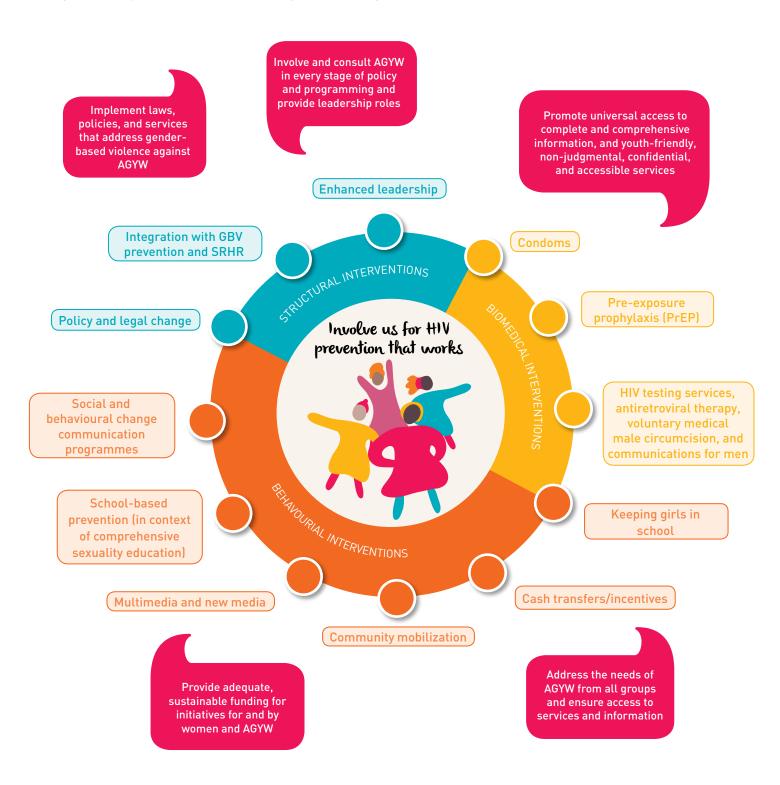


"No clear messages targeting AGYW on how to access, where to access and why they need it." KENYA

Other concerns included structural problems with PrEP implementation, promoting PrEP when ART coverage is not universal (Uganda), and around the quality and sustainability of PrEP supply.

Participants' suggestions to improve PrEP availability and acceptability included intentional packaging of information to cater to a young audience, including emphasizing the use of condoms and abstinence as a way of keeping AGYW safe and clearly outlining both the advantages and disadvantages of taking PrEP.

Figure 1: HIV prevention for adolescent girls and young women



Adapted from UNAIDS (2016) HIV prevention among adolescent girls and young women: putting HIV prevention among adolescent girls and young women on the Fast-Track and engaging men and boys. The infographic simplifies the UNAIDS recommended strategy mix and places adolescent girls and young women at the centre and in the context of their key priorities for HIV prevention that works.

# ACCESS TO COMPREHENSIVE REPRODUCTIVE HEALTH SERVICES INCLUDING SAFE ABORTION AND A CONTRACEPTIVE METHOD MIX

Participants were asked to describe access to reproductive health services in their countries, including to safe abortion and a contraceptive method mix. Respondents identified restricted access to abortion in particular, including information as well as services. Legal restrictions on access to safe abortion were described as driving AGYW to access unsafe abortion or to attempt to induce miscarriage: "[restricted access] "compels the perpetuation of the practice in secrecy and often under unsafe conditions." UGANDA

"In Namibia abortion is not legalized, hence women, mostly young women, tend to be forced to do practical 'trial and error' or perform what they heard their friends have done to get rid of a pregnancy." NAMIBIA

Some participants pointed to a lack of understanding of the laws around abortion and suggested AGYW are more likely to seek unsafe abortion services as a result, even in settings that offer legal abortion services. Abortion was also described as highly stigmatized.

"The AGYW becomes the talk of the whole community and there it a lot of stigmatization attached because the girl is regarded as a prostitute."

MALAWI

One participant from South Africa identified a **lack of information** provided by the government around abortion, and that in general:



"The information on SRHR is very much heteronormative and pathologizing of young people as sexual beings."

Many highlighted problems with the **health system** and services, particularly in a lack of youth-friendly services, including those that offer contraceptive options. Judgemental attitudes from healthcare workers in general were also seen as a challenge, with some suggesting AGYW did not seek contraceptives because of this:

"Health worker attitude also stops young women from getting services. They are told they are too young to get contraceptive." MALAWI

Information and commodities to support prevention of pregnancy was identified as an important intervention to prevent unplanned pregnancies, and as an extension, abortion.

#### ACCESS AND AVAILABILITY OF CONDOMS

Barriers to effective access to condoms for AGYW, described by participants, centred on **confidence**, particularly in accessing condoms and negotiating their use with male partners.



"I also tried the negotiation part and it's tricky because the guy kept saying it's ok we will use it.... let's wait a bit. I think he was hoping that I will just drop the condom talk...some AGYW just give up." KENYA

**Stigma** around AGYW's sexual behaviour was also, once again, identified as a major barrier, including belief that young people should be abstinent, resulting in participants reporting judgemental attitudes while purchasing or asking for condoms. Participants suggested that accessing condoms was taboo and provoked judgements from the community: "It's very hard for an adolescent to walk to a pharmacy or health centre and ask for a condom." KENYA



"[It's] unheard of for a girl or women to carry a condom, when you do you're deemed promiscuous."
KENYA

Some participants pointed to a **lack of information** and education about condoms as particular barriers, including gender-based perceptions that such knowledge was inappropriate for AGYW to hold. Additionally, it was suggested that some AGYW perceive condoms as only useful for preventing pregnancy, rather than also as protection from acquiring HIV and other sexually transmitted infections.



"The [less] you show you even know about sex, the more praise and trust you receive from your family and community." KENYA



"Young people lack information on how and where to get [condoms]." UGANDA

Particular challenges in accessing information and condoms, and safe spaces to discuss and learn about their use, were identified for AGYW with disabilities, and those in rural areas.

A number of participants identified that there is some resistance to public sector condoms, as young people want flavoured and coloured condoms with different packaging, that is not normally available through publicly-provided services.

Recommendations to improve condom usage among AGYW included: provide more private ways for AGYW to access condoms; involving parents in the conversation – use sensitization programmes to help them understand the need for correct information on ways AGYW can keep themselves safe (including condom use); and empowerment and education of AGYW.



"If young girls took initiative to have condoms on them and insist that they have protected sex, I believe it'll reduce the risk of HIV." MALAWI



"I think one strategy would be to normalize the conversation about sex and protection." KENYA

## SOCIAL AND BEHAVIOURAL CHANGE PROGRAMMES

Participants were asked to identify what social and behavioural change programmes were available in their countries and comment on their usefulness as an HIV prevention tool for AGYW.

While the participants were able to provide examples of social behavioural change programmes taking place in their countries, many highlighted problems with reach of programmes, including rural areas being neglected, difficulties in access for some AGYW and leaving young men out.

"As much as these social behavioural change programs are concerned, us as AGYW with disabilities there will always be a gap." ZIMBABWE

Some participants pointed to a lack of adaptability of the projects as a challenge in meeting the specific needs of the target group of AGYW.

"They should provide the messages according to the target groups NEEDS hence there is a need for an assessment for each target group before delivering the messages ... to achieve that, you need to ask me before implementation." MALAWI

The challenge of achieving effective behaviour change was also identified by one participant: "Knowledge and changed attitude doesn't automatically translate into behaviour change." MALAWI

Many participants brought up concerns about **sustainability and long-term impact** of behaviour change programmes.

"The programs are usually projects that have a short timeframe and are effective only during that time that they are being implemented. Once they phase out, everything goes with them." MALAWI

"What happens to the beneficiary when funds run out? I fear we are creating or have created donor dependency syndrome."

Participant suggestions for improvement included: facilitate community ownership, provide support, and ensure access to programmes for those with disabilities (including educational tools in braille, large print, etc.); engage AGYW in the planning process; and integrate with other services.

#### SCHOOL-BASED HIV PREVENTION

Focus group contributors were asked about availability and effectiveness of school-based HIV prevention in their countries. A number of programmes were identified and challenges to their implementation were discussed. Participants suggested that **parents are often resistant** to school-based programmes and that they feared exposing their children to topics on sex too soon. Involvement of parents, guardians, chiefs, and religious leaders in planning was identified as

an important element for successful programmes.





"The only way parents will get comfortable with this is if we design particular messages and information for particular groups of people."

UGANDA

Participants identified the need for age-appropriate messages, consistent teacher training, and for effective delivery of methods to engage students.



"Key messages for primary school children can't be the same as those for university students." UGANDA



"Not all the teachers have been trained even the trained ones see it as a burden or extra work load on them so the lessons will be neglected." ZIMBABWE

"Talking from experience, some of the subjects I learned just to pass... some I can't even remember the content... I think service delivery should be the most prioritized aspect." ZIMBABWE

Others suggested that there is a gap for AGYW in tertiary settings, and that it was critical to ensure HIV prevention education continued beyond secondary schools.

Participants want programmes that are **inclusive** of difference – sexual orientation, disability, age, or culture.

Many reported a preference for peer-led education as a delivery mechanism for school-based HIV prevention.



'Students easily open up because you appear like a sister figure than an adult who is like a parent." UGANDA

'School-based peer-led facilitation will be one of the most powerful tools if [students] are trained and mentored to deliver messages to their fellow peers." ZIMBABWE

#### **UPTAKE OF SERVICES BY MEN AND BOYS. INCLUDING HIV TESTING, ANTIRETROVIRAL** THERAPY, AND VOLUNTARY MEDICAL MALE **CIRCUMCISION**

The UNAIDS guidance features a strategy to improve HIV prevention for AGYW by increasing the uptake of HIV prevention services by men and boys. Asked to share their views on this strategy, participants primarily focused on the specific services listed, and the challenges associated with them. In particular, their responses focused on voluntary medical male circumcision (VMMC) and lack of understanding of its benefits for women: "Personally do not see the benefit of VMMC to women." SOUTH AFRICA

Participants also highlighted the need for more counselling and education for men and boys about the benefits of VMMC and the need to continue condom use, and the need for **community sensitization** campaigns.



"Men tend to think that it is safe to have unprotected sex [after VMMC]." BOTSWANA

Immediate initiation of antiretroviral therapy (ART) for men and boys testing positive for HIV was seen as potentially challenging due to stigma about HIV treatment.

Broadly, respondents suggested that achieving success in this strategy depended on: addressing **norms about** masculinity; increased use of social media forums to advocate for use of these services; and nominating and supporting male champions.



"Changing norms around masculinity has to start from the communities [and the homes]." UGANDA

"Good to have a role model who has created impact in his family, has changed his community, and inspires other boys and men." UGANDA

#### INNOVATIVE **MULTIMEDIA APPROACHES**

Media campaigns and information materials were widely regarded as positive approaches to reach AGYW with prevention

and catchy messages information. Different media were identified

Work with us

to create relevant

as positive, including radio for rural populations with limited access to other options, **blogs** written by young women themselves, and engaging, entertaining approaches such as skits, plays, and musicals. Tailoring content to the audience, including variety and relevant and catchy messages, was also prioritized.



"I believe internet has a more effective way of preventing HIV as there is a variety of information tailored to each individual." BOTSWANA



"To make [the messages] more effective, popular media channels should be used and catchy messages in local languages." UGANDA

Appropriate content was identified as key, content that respects AGYW's choices and agency, including over their sexuality.



"Value and respect young women's choices and contributions on matters of SRH." ZIMBABWE



"[Poor content] problematizes young people as sexual beings." SOUTH AFRICA

Priority topics identified that should be included in media campaigns included: age-disparate relationships and their consequences; information on sexual networks; information on where to access HIV/SRH services; messages that encourage disclosure of HIV status to partners; and, body changes that occur in AGYW.

In order to be effective, messages should be empowering, simple, and informative, and include information and connection to sexual and reproductive health services and real life stories. Familiar language should be used to enable access, and campaigns should ensure a wide geographic reach. Negative messages focused on risk and disease were not likely to be effective, according to participants. Additionally, participants advocated moving beyond limited topics and focus:



"Everything is always HIV centred and doesn't take into consideration of other SRHR aspects (abortion, contraception, sexual violence, etc.)." SOUTH AFRICA

#### **CASH TRANSFERS AND SOCIAL GRANTS**

AGYW taking part in the focus group identified that to their knowledge, only a few organizations were implementing cash transfers as a tool for HIV prevention. The strategy was described positively by participants, and reported to be welcomed and acceptable to AGYW.

"Some have started savings groups where they give soft loans to each other and have started small scale businesses." KENYA

"It's way overdue and the cash transfer [programme] should have started yesterday if we really want to achieve 90-90-90 targets." KENYA

Participants identified that cash transfers should be **part of a package** of HIV prevention tools and have a wide geographic reach. Other interventions that work to keep AGYW in school and empower them in their communities need to be considered alongside cash transfer programmes.



"If not offered within a mentorship package it may yield unbalanced results." ZIMBABWE

#### **Sustainability** was

identified as a challenge, with participants advocating that there must be commitment to investing in cash transfer programmes in the long-term.

The need for programmes to be **adaptable** was also outlined, with one participant noting that AGYW are diverse and the motivations for their behaviour may not always be linked to poverty:



"Adolescent women and young girls' needs are diverse and range from makeup to nice clothes. Not all girls that engage with older men are actually poor."

UGANDA

#### **KEEPING GIRLS IN SCHOOL**

Efforts to keep girls in schools, identified during the focus group discussion, included provision of bursaries and cash transfers, and raising the legal minimum age for marriage. Achieving success in these efforts depended, according to participants, on effective partnerships, engaging parents, and other stakeholders, and sustainability of support to remain in school.



"Organizations to work together and provide different services." MALAWI

"More holistic approaches – work with parents and all cultural gatekeepers and influential stakeholders especially at community level. And partnership – that's the major key!" MALAWI

"It takes more than a notebook or school uniform for a girl to stay in school. She will go to school, yes, but chances are high that she will drop out." MALAWI

Particular efforts were also identified as necessary to meet the specific needs of different groups, including pregnant girls, those with disabilities, rural/remote AGYW, orphans, and AGYW from child-headed families

"We have learned it takes a lot more [to keep girls in school] especially for teenage mothers – we have found ourselves paying for day care services for girls with children who have no support in their homes...they need a

whole new set of services on top of the ones being provided to other girls." MALAWI



"We plea with the policy makers to make these facilities reach the disabled communities and vulnerable girls." ZIMBABWE

Participants suggested that programmes should also consider university students and how to minimize fees to reduce drop out. "Malawi for once should make Education a priority & available to all even in remote places."

**Female hygiene** and access to products was identified as a key challenge. Many participants highlighted that AGYW often miss school when they do not have access to sanitary wear, provision of which could enable girls to stay in school.



"This deters progress and still sends them back out there to people that wanna take advantage of them." UGANDA



"To keep a girl in school...they should look into free sanitary pads for girls." MALAWI

Other challenges to keeping girls in schools included: lack of provision of food, educating parents about the need to keep girls in school, poor standards of education, scarcity of teachers, AGYW with disabilities are neglected from school curriculum, and a lack of recreational facilities.



"Most UPE schools do not provide food for students and this hinders their motivation to continue school." UGANDA



"Our town councils have put up buildings everywhere and children have no places to be children."

ZIMBABWE

#### ADDRESSING LEGAL BARRIERS

For this aspect of the discussion, a range of barriers were shared, and participants asked to reflect on what efforts were in place to address them, what more could be done, and what key messages they felt policy-makers needed to take on board in order to address legal barriers and better meet the needs of AGYW. The following is a selection of key messages linked to specific legal barriers to HIV prevention that AGYW face.

**Age-disparate relationships** – "One of my biggest struggles is without entertainment industry that has so

much influence with youth to join us in this fight. Maybe we can be effective then. Right now, they perpetuate the problem by glorifying Sugar Daddies and objectifying women." SOUTH AFRICA

Child marriage – "Empowering girls so that they are selfsufficient, educating communities about this, changing attitudes among parents and community leaders and of cause... creating legislative change and enforcing laws."

**Gender-based violence legislation** – "The legislation is there. It is the woman's mentality we need to work on. Again we go back to the issue of empowerment." ZIMBABWE

"We have a challenge of girls and women being abuse in public spaces and transport by touts and even physically harassed but because there is no law specific to such acts and not enough education on how they can report such violations, what laws govern that and definition of a specific violation." ZIMBABWE

**Key populations** [sex workers, men who have sex with men, women who have sex with women and transgender people] –"If we really want to succeed in our fight against HIV/AIDS we have to recognize them and treat them like any other person would be treated so that they don't have to live in hiding thus creating room for them to access SRHR." ZIMBABWE

**Age of consent** – Consent to test for HIV "I would reflect this to my own story where I came to know about my HIV status when I was 16 and had a severe cough. The nurses at the Health Centre couldn't allow me to take the HIV test without a parental signed consent." RWANDA

AGYW lack information on the legal system and often do not know their rights – "I think the major reason that they are not effective is because the AGYW lack information



on the legal system and we still have a challenge telling the girls that it is actually their right and no one should give it to them." UGANDA



# INTEGRATING STRATEGIES TO ADDRESS GENDER-BASED VIOLENCE

The UNAIDS guidance includes a strategy to integrate HIV prevention with GBV prevention and SRHR services. Participants were specifically asked to think about GBV, and the integration of services to address GBV in other services, what support was available to AGYW experiencing GBV, and what

more could be done. This topic elicited significant discussion, with participants sharing personal experiences of violence, and accessing services for support.

Participants highlighted the need for **targeted**, **responsive and accessible support**, including tailored support to meet the needs of the woman affected. Services should also ensure they meet the different needs of all vulnerable groups, including lesbian, bisexual, and transgender AGYW and those with disabilities.

"Some need counselling and remain in relationships, some need a way out, some want out and need financial alternatives to what they had for themselves and their children." ZIMBABWE

"[People with disabilities] do not even know what GBV is they are vulnerable to violence and do not know what is right or wrong." ZIMBABWE

The links between GBV and **economic empowerment** were highlighted:

"We should not forget that GBV is an economic problem above everything else and it feeds directly into the dis-empowerment of women in all aspects of life." ZIMBABWE

Barriers to accessing GBV services identified by AGYW taking part in the discussion included **stigma**, **lack of understanding of GBV**, the **normalization** of violence, and perceptions that it was a **private or domestic issue**.

"The messages against gender based violence are not clear... I don't know everything that constitutes gender based violence." MALAWI

"GBV is termed a bedroom issue, whatever happens in the house cannot be told outside thus women suffer in silence." MALAWI

"Whatever happens in the marriage tends to be normal to the women. And the notion that man is the head of the house is supreme." MALAWI

In addition, legal protections that apply only within marriage, and fail to protect those who are not married, were seen as a challenge.

"Our laws and messages on GBV are biased towards married women. Not really targeting AGYW. This then affects how these cases are treated by lawmakers like the police." MALAWI

Many participant highlighted that GBV is deeply ingrained in **cultural and social norms**, and that messaging must address these norms and beliefs if it is to be effective.

"There is need to understand that GBV is centuries old and had deep roots in societies, so to end there must efforts that a widely spread, that address modern GBV with understanding and learning from deep historical challenges." ZIMBABWE

"The messages towards gender based violence are not clear as some people see these messages as teaching them to derogate from cultural norms they are accustomed to." BOTSWANA

"Advocacy should now target changing the mindsets of communities to fight and end GBV and start working towards a GBV free generation." ZIMBABWE

Further, the need for **follow up** and ongoing support services, referral to resources such as safe housing, and other linked interventions were seen as key.

The need to inform AGYW and men and boys about violence in all its forms, to enable them to identify violence and understand what support was available was highlighted. Participants suggested that in some cases, emphasis is put on rape in GBV messaging and programming, but **other forms of violence** are left out of programmes.

"The messages that are out there are mostly on rape but not all forms of violence which is sad because we walk through life never knowing what is really violence and what is not even for the perpetrators." KENYA

Participants strongly agreed with the need to **integrate GBV services into HIV and SRHR services**. This included



calls for family planning clinics to consider and address the potential experiences of GBV that AGYW accessing services might be facing, and support to

address these. Integration was seen as essential to successfully addressing the linked issues of GBV, HIV and SRHR.

"Most of the time when a service is offered to a woman, the forms of power in the family have to be looked into." ZIMBABWE

"A woman cannot suggest to using condoms if she fears her husband or boyfriend even when she knows that he is seeing other people outside." KENYA

"GBV in many cases and programs is handled as a unique issue and hence isolated from the general HIV and SRHR programing." UGANDA

"New infections will continue to exist if GBV is treated as a separate program from HIV and SRHR programs." BOTSWANA

Participants therefore recommended effective integration, and the **provision of services in all healthcare facilities**, regardless of where they are located. They also called for support groups and safe spaces, 'one-stop' centres, training of healthcare providers, and programmes specifically targeting AGYW.

"One-stop centres have been constructed in several Health centres and most are in remote areas. There is a police officer, counsellor and hospital staff specifically taking care of GBV cases...police officer to follow up the case, counselling services to be provided to the survivor and hospital to do its work as well." MALAWI



"Give healthcare workers the necessary skills to help deal with such issues." MALAWI

Finally, AGYW called for ongoing and widespread information campaigns and community sensitization efforts, including campaigns that involve and target men and boys: "Men and boys must be educated and involved in campaigns." ZIMBABWE



"Information drives should happen often like the vaccine drives because GBV is a disease that eats our girls and young women slowly and silently." KENYA

#### **AGYW IN LEADERSHIP ROLES**

While there was agreement that AGYW should be involved in leadership roles in HIV prevention, and participants described some efforts where this was the case, this element of the discussion primarily focused on barriers, including the negative experiences AGYW faced when participating in leadership positions. This included **sexual harassment** from men also in leadership positions.

"Truth be told the more you engaged in advocacy spaces the more vulnerable you become... also sometimes this harassment also comes from fellow young men in leadership as well and it really demotivates."

ZIMBABWE

"Many AGYW are exposed to sexual harassment when tabling points and the decision has to be made by men on board with more deciding powers... many AGYW are involved in planning processes but as tokens." UGANDA

"Women are seen as "loose" in politics." ZIMBABWE

Other **negative views of women** in leadership positions were described, including being constructed as victims or understood as being unable to equally participate.



"In most cases when the young women are engaged they are viewed as victims who need help. Thus the leadership part is not pronounced." ZIMBABWE



"Culture looks at a woman or as a low person who can't raise constructive issue and a times they are offended because of the nature." UGANDA

In some cases, barriers were more related to lack of knowledge of available opportunities to take up leadership roles. "Young girls are unaware of opportunities to engage with government." ZIMBABWE. In others, lack of access was the main barrier.

"The challenge is that a lot of men are sitting in positions, making decisions about women's lives and hogging those positions and not actively engaging women and other decision making and implementation." SOUTH AFRICA

To address these challenges, many participants called for mentorship programmes to provide support to AGYW. Safeguarding mechanisms were also described as necessary, including clear guidelines on how to engage with AGYW in organizations, policies against sexual harassment, and mechanisms to report it.

"One gaining all the qualities of a good leader and thus rewarding her with the opportunity to mentor others is a practical way to me to instil leadership to the AGYW." KENYA

#### **FIVE PRIORITIES: WHAT AGYW WANT TO MAKE HIV PREVENTION WORK FOR THEM**

The focus group closed out with a call for adolescent girls and young women taking part to identify their key messages, that they felt HIV prevention policy-makers and programmers needed to know in order to better meet the rights and needs of AGYW in HIV prevention. Five major priorities emerged, outlined here in the words of adolescent girls and young women themselves.



#### Involve and consult AGYW in every stage of policy and programming and provide leadership roles

"If young people are able to contribute to the policies that determine how SRH services should be rendered, they will fully participate and receive the services. I'm for youth participation in policy formulation." ZIMBABWE

"Nothing for us without us. Consult, involve and include us in policy formulation, programming and implementation for sustainable development!" MALAWI

"Many AGYW are involved in planning processes but as tokens. Their opinions are not comprehensively addressed and might not even come out on the final document or project. AGYW must have a seat on a final decision-making body and need to be involved throughout the programme development processes." UGANDA



#### Promote universal access to complete and comprehensive information, and youthfriendly, non-judgmental, confidential, and accessible services

"We need every young woman in Zimbabwe to have the freedom to make a choice to access comprehensive SRHR services. Every young woman should be allowed to make a personal choice based on correct information which should also be easily accessible and the services should be safe and free." ZIMBABWE

"PEP and PrEP should be readily available for everyone."

"Open discussion about SRHR and the use of condoms in all spheres." ZIMBABWE



#### Address the needs of AGYW from all groups and ensure access to services and information

"I would like to see health policies which are inclusive and addressing disability issues. I would love to see the policies empowering us." ZIMBABWE

"Comprehensive SRHR services should be made accessible to all women regardless of age, sexuality or race based on all the SRHR needs for women of all diversity." ZIMBABWE

"Services that target the youth and young women should be separated from mainstream health system for women and girls have got their own health concerns that need to be addressed separately and with specialised individuals." MALAWI



#### Provide adequate, sustainable funding for initiatives for and by women and AGYW

"Leaders should allocate adequate resources to women led and women serving initiatives in HIVrelated work to avoid the issue of underfunding which is compromised by patriarchal resource allocation which prioritises men's issues." ZIMBABWE



#### Implement laws, policies, and services that address gender-based violence against AGYW

"We need a long term solution on GBV in terms of policy making." KENYA

"Clear and better response to gender-based violence where-by policies and laws are not overlooked." UGANDA



"As a Working Group member, I have been touched by the amazing views young women and girls must state and having to hear from them what they want clearly showed we have been invited to the table but so often have not shared in the decision-making."

ANNAH SANGO, WORKING GROUP MEMBER, ZIMBABWE



"Advocating for empowerment of AGYW and the promotion of AGYW in addressing current unequal gender norms that reduce AGYW ability to make informed choices about their own

sexuality, is key to reversing the dramatic upward trend of HIV infection among AGYW."

RESTY NALWANGA, WORKING GROUP MEMBER, UGANDA

#### UNLOCKING CHANGE

The following outcomes have stemmed from the focus group participation and findings:

- Education on PrEP versus PEP, based on UNAIDS definitions
- Encouraging a practical understanding of SRHR, based on WHO and UNFPA definitions
- Creation of an online clearing house for HIV prevention, advocacy, leadership, and disability events
- Key messages for a strategic meeting around HIV prevention and SRHR for AGYW
- Ongoing virtual mentorship
- Gathering feedback for the DREAMS (Determined, Resilient, Empowered, AIDS-Free, Mentored, and Safe) initiative meetings
- Nomination and support for AGYW to attend the UNAIDS HIV meeting in Victoria Falls, Zimbabwe

- Guidance and support for blogs written by AGYW focusing on HIV prevention and the UNAIDS prevention guidance
- → Development of a guide for social media advocacy
- Running a visual campaign in partnership with the #WhatWomenWant working group and focus group members, focusing on issues ranging from ending child marriage to supporting comprehensive sexuality education



## Advocating for #WhatWomenWant





Advocacy on social media platforms focused on significant dates and events.

including the Young African Women's Summit and the 9th African Union Gender Pre-Summit held in January 2017. Both focused on the theme: harnessing the demographic dividend through investments in youth: empowering young people, especially young women, for leadership and civic participation. Campaign messaging included calls for investment in young African women's leadership and civic participation for a gender-transformative HIV response and funding mechanisms to support the leadership and meaningful participation of AGYW. Campaign memes were widely shared for the International Women's Day on 8 March, calling for the rights and needs of women and young women in all their diversity, and the impact of HIV to be centred in the global agenda for gender equality.

In just one week, from 25 February to 2 March 2017, #WhatWomenWant was tweeted:\*

701 times and from 300 different users, with a reach of 774,729 accounts and 2,368,957 impressions.

#WhatWomenWant is not a hashtag unique to this campaign and this data reflects overall usage of the hashtag rather than a breakdown specific to this campaign

#### **AMPLIFYING ADVOCACY: AGYW HIV** PREVENTION TWITTER CHAT

To reach out to a wider audience of decision-makers, advocates, allies, and adolescent girls and young women, ATHENA convened a Twitter chat, on 28 February 2017. AGYW participating in the different arms of the project were encouraged to participate and support this, and given a guide to signing up to and using Twitter effectively.

Key guestions were shared during the chat and participants invited to copy key policy- and decision-makers into their tweets as they identified their priorities. A graphic showing the Twitter handles of National AIDS Control Councils, relevant Ministries, UNAIDS, and other decision-makers in Kenya, Malawi, and Zimbabwe was shared to facilitate this.

During the chat, almost 130,000 accounts were reached, with more than 1.2 million impressions achieved. The chat generated significant activity and key messages and priorities surfaced, but was less effective at engaging AGYW than WhatsApp.

















Muthoni Muchemi @Penn\_Sonia · Feb 28

**43** 5

Unmarried sexually active girls aged 15 to 19 have not had their

contraception needs met due to age restrictions. #WhatWomenWant







#malawi #WhatWomenWant @NetworkAthena msges mostly show men as sole decision maker when it comes to sex

#### ACCOUNTABILITY IN ACTION: UNAIDS ZIMBABWE VIRTUAL DIALOGUE AND ONGOING DISCUSSIONS

UNAIDS Zimbabwe engaged in a virtual dialogue, using WhatsApp with AGYW in Zimbabwe. The aim of the dialogue was to facilitate meaningful and direct engagement of AGYW with decision-makers with a focus on responsive and accountable HIV prevention programmes and services.

56 AGYW engaged in a virtual dialogue with UNAIDS Zimbabwe using a WhatsApp group created for that purpose. Staff members from UNAIDS Zimbabwe participated, providing updates on current and upcoming activities and priorities, and AGYW were invited to comment and feedback on these, ask questions, and make recommendations.

54 AGYW continued to engage in an ongoing discussion on HIV prevention for AGYW in the Zimbabwe WhatsApp group on the following topics: cash transfers, keeping girls in schools, legal barriers, and integration of SRHR services with gender-based violence.

A key topic that emerged from the UNAIDS Zimbabwe virtual dialogue was engagement with AGYW with disabilities. Many participants highlighted concerns of AGYW with disabilities being left out of programmes: "Young women and girls with disabilities seem to be forgotten most times yet we must leave no-one behind."

"There is a group of people with disabilities that I think are being left out, [especially] those with speech and hearing impairment. What is being done to get the message of HIV/AIDS across to them since they use sign language as a mode of communication?"

Participants voiced interest in how they could more effectively be involved in programme planning and implementation:

"I represent the much and most-at-risk population of women with disabilities and am also disabled. In as much as all your programmes are good and targeting young people, I feel not much is being done for us about HIV, SRH and AIDS programming ... in your programmes how are you involving AGYW with disabilities in addressing these issues?"

Other issues raised were how rural marginalized communities were being reached, how young girls who sell sex were being targeted for intervention, and how justice for those who have experienced gender-based violence was being served.

Participants wanted to know more about practical solutions to issues that were important to them, such as getting young women back into school:

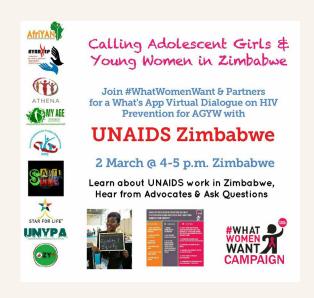


"I want to understand if there is any way we can get them back in class or empower them with better ways to get the money."

One participant wanted to know about strategies for implementation to target the key issues highlighted by participants:

"How are you hoping to cascade such issues to implementation stage considering they have not been prioritized in the policies that you are advocating for?"

The opportunity to engage directly with UNAIDS staff allowed AGYW to identify their priorities, ask questions, and influence strategy and implementation. UNAIDS Zimbabwe staff provided insights into their programming and policies at country level, and engaged in the discussion effectively. This model could be easily replicated in different settings, with policy-makers and programmers from government, multi-national bodies, NGOs, and the private sector.



#WhatWomenWant

starting it, setting

#WhatWomenWant

Sexual and

Health and

Rights

Reproductive

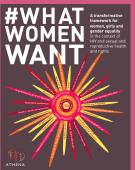
is to be leading

it, and bringing their solutions

# **#WHATWOMENWANT DAY**

On 6th April 2017, ATHENA led the inaugural #WhatWomenWant day, a global takeover of social media to promote the campaign and its key messages. Over 600 unique users in 48 countries tweeted using the #WhatWomenWant hashtag, reaching 960,000 unique Twitter accounts with over 1.2 million impressions. It was the top trending hashtag in New York, during the 50th session of the Commission on Population and Development where advocates, government representatives, and decision-makers were gathered to discuss sustainable development while also simultaneously trending in Washington DC and Nairobi.

Young women, activists, feminists, allies, policy-makers, decision-makers, and even a member of the Kenyan Parliament, all took part, using the hashtag to demand action to fulfil #WhatWomenWant. Demonstrating the intersectional experiences of young women, many people taking part used other linked campaign hashtags, with some of these reaching over 100,000 joint uses, including: #TheAfricaWeWant, #SRHRDialogues, #PREP, #CPD50.



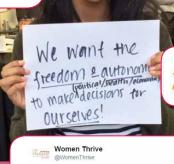
ATHENA also used the day to launch #WhatWomenWant: A Transformative Framework for women, girls and gender equality in the context of HIV and sexual and reproductive health and rights – the result of a six month consultation in 2016 with young women globally.

ViiV Healthcare We're proud to support #DREAMS: giving #adolescent girls educational tools to protect

You can see the tweets and messages from the day at: https://storify. com/NetworkAthena/ resounding-voiceson-whatwomenwant-

against #HIV bit.ly/2eMvXbS

#WhatWomenWant



WE-Change @WEChangeJA · Apr 6 Young women have sex. Get over it. #WhatWomenWant pic twitter.com/39aRL6uCD3

pic.twitter.com/yvrqb1G2df

Akumaa Mama Zimbi @ @Akumaa - Apr 7

This is #WhatWomenWant #HIVprevention

#GhanaProtectTheGoal #NoStigma #endingAIDS @G\_Haile @JanMBeagle @MichelSidibe @UNAIDSGhana @UNAIDS

Based on what #AllianceMembers tell us #WhatWomenWant is to be consulted on their countries Nat'l Development Plans on SDG5 RETWEETS LIKES

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musavi valarie

from HIV, bodily freedom, safe and legal abortion, #endvaw #SRHRDialouges

- Follow

#WhatWomenWant: safe sex, protection

## From guidance to action

There is a multitude of guidance, programmes, policies, strategies, and evaluations on HIV prevention for adolescent girls and young women. We know, now, what to do, and there can be no question over why we should. Adolescent girls and young women face a disproportionate burden of HIV, driven by social and structural factors. These also generate a burden of disempowerment, gender-based violence, limitations on education and opportunities, and prevent AGYW from realizing their potential, and societies the world over from benefiting from their ideas, contributions, and leadership.

The 2016 UNAIDS guidance on HIV prevention among AGYW is welcome for bringing together the strategies and conceptual framework that represent best practice in delivering on HIV prevention for this group. But guidance alone is never enough. If it was, we would have reached the goal by now. So we must ask, what has prevented turning the tide of the HIV epidemic for AGYW? Why is there still so much left to do? Many of the barriers and challenges that have impeded success have been identified and articulated by the adolescent girls and young women who participated in this #WhatWomenWant process.

They have described the social norms around 'appropriate' knowledge and behaviour for AGYW that prevent them accessing information or services.

They have articulated the practical barriers of access, for girls in rural areas and young women with disabilities, among so many others.

They have described the epidemic of gender-based violence they continue to face, in their homes and communities, and even in advocacy and leadership settings.

They have told us about the lack of knowledge about new prevention technologies such as PrEP, which prevents AGYW from fully realizing the benefits of scientific progress.

They have articulated the failure of negative, shaming, and risk-based prevention messaging in reaching and convincing AGYW.

Support us to be safer and stronger while we work to realise our rights and those of all AGYW

They have identified the problems caused by short-term projects, unintegrated services, and policies that never move from paper to action.

Now, we must listen.

Through this process, we have engaged hundreds of adolescent girls and young women, across countries and communities, through different tools and platforms, to inform them about the UNAIDS guidance, to consult them about their values, preferences, and experiences of HIV prevention, and to engage them in direct accountability and advocacy. This process must be ongoing, and repeated in each country, region, and community where HIV prevention services, information, and tools for AGYW are yet to achieve their aims. Simple, accessible tools can facilitate a deep engagement with AGYW that can inform HIV prevention efforts and improve their chances of success.

Without prioritizing the voices, expertise, and experience of adolescent girls and young women, without fostering their leadership or engagement, we will continue to be outpaced by the epidemic. Getting on the Fast-Track depends on hearing, implementing, and prioritizing #WhatWomenWant.

#### **ABOUT ATHENA INITIATIVE**

ATHENA's aim is to advance gender equality and human rights, working through global health policy and practice – and in so doing to realize a world where women in all their diversity have the power, choice, and agency to make and enact their own decisions regarding their sexual and reproductive health and wellbeing, and to claim their human rights: where HIV is no longer a public health emergency; and where gender-based violence in all its forms is eradicated.

As a global network of organizations and individuals, we bring expertise through lived experience, and work through on-going partnerships rather than isolated projects. Our approach is based on a durable and transformative model of change: seed change from the bottom up and ensure that global processes are reflective of local realities, and vice versa.

We mentor new young women leaders, invest in lasting collaboration and mutual knowledge exchange, bridge movements towards a more inclusive, stronger women's rights and gender equality movement, and in so doing strengthen and invest in women-led civil society.

www.athenanetwork.org





# Acknowledgments #WhatWomenWant ATHENA leadership team:

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