

Health Systems Research Unit:  
Research Briefs

# The HERStory Series

Lessons learned from implementing a PrEP programme for adolescent girls and young women in South Africa

## SUMMARY

- Daily oral pre-exposure prophylaxis (PrEP) is highly efficacious for HIV prevention.
- Adolescent girls and young women (AGYW) are regarded as a priority population in South Africa's National Strategic Plan (NSP) for curbing HIV, TB and STIs: 2017–2022 and they have been prioritised for PrEP delivery in South Africa.
- Numerous sociocultural, behavioural, structural and physiological factors contribute to the disproportionate HIV risk that AGYW in South Africa face.
- There is an urgent need for effective female-initiated HIV prevention strategies targeted at AGYW, to reduce HIV incidence among this population.
- Participants in the study described several challenges associated with PrEP uptake, adherence and acceptability, including AGYW fears of side effects of PrEP, and AGYW preference for injectable PrEP over a daily oral tablet.
- Our findings highlight the critical role of parental and community acceptability and support of PrEP as a key enabler in the successful PrEP demand creation, provision, uptake and adherence among South African AGYW.

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**These research briefs were developed by scientists at the South African Medical Research Council's Health Systems Research Unit to share findings from studies conducted by the organisation.**

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- Challenges relating to AGYW, community and parental resistance to PrEP described by implementers were due to a lack of accurate information about PrEP, and PrEP stigma linked to associations with antiretrovirals and assumptions of promiscuity.
- There is a need to address logistical challenges related to procurement and stockouts of PrEP to mitigate supply interruptions of PrEP, through supply monitoring, forecasting, database management, distribution and delivery, as unreliable provision negatively impacts acceptability, uptake and retention.
- The successful implementation of PrEP programmes at a national level requires collaboration and on-going engagement with communities, the government health sector, and non-governmental organisations, inclusive of the promotion of PrEP outside of the clinical setting as a means of increasing acceptability and achieving successful uptake and scale-up of PrEP services.

### CONTEXT OF HIV AMONGST SOUTH AFRICAN ADOLESCENT GIRLS AND YOUNG WOMEN

- South Africa's HIV epidemic is the largest in the world, and the fastest growing.
- There exist significant differences in HIV incidence and prevalence by age and sex; women face disproportionate HIV burden throughout the life cycle, but this gender disparity is most pronounced among adolescent girls and young women (AGYW) aged 15–24 years, whose HIV prevalence is 3.3 times greater than their male peers.
- South Africa's epidemiological profile shows that while new HIV infections do occur in adolescent girls below 15 years, incidence is substantially higher in the 15–24 age group, given that the majority (92.4%) of AGYW have their sexual debut (first sexual activity) at 15 or older.

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### RATIONALE FOR PREP PROVISION TO AGYW

- Gendered power inequities are weighted in men's favour, limiting AGYW's power and agency to use condoms
- Gendered socio-economic power disparities contribute to AGYW's vulnerability to HIV infection, through increasing their likelihood of engaging in transactional sex, condomless sex, and age-disparate sexual partnerships
- Girls and women often engage in sex that they do not want, do not like, or are not comfortable with, to maintain relationship security and to avoid violence from their sexual partners
- The lack of agency that AGYW have to control condom use, and the timing of sex (when sex takes place), decreases their likelihood of success in using coitally-dependent HIV prevention products, indicating that other HIV prevention options, that give AGYW more self-efficacy and agency, are critical for this population.

### PRE-EXPOSURE PROPHYLAXIS (PREP)

- A daily dose of oral PrEP has been shown to be highly efficacious, giving > 90% protection against HIV acquisition when taken with high adherence, and evidence shows that PrEP offers powerful protection for women.
- The South African Health Products Regulatory Authority (SAHPRA) approved the use of daily oral PrEP in 2015, for adults and adolescents > 35 kg.
- Due to their disproportionate HIV risk, AGYW aged 15–24 have been prioritised for PrEP delivery in South Africa.
- Although biomedically efficacious, PrEP effectiveness is dependent on access, adherence, and persistence.
- Access, use, and adherence to PrEP also requires substantial commitment and support from health care providers.

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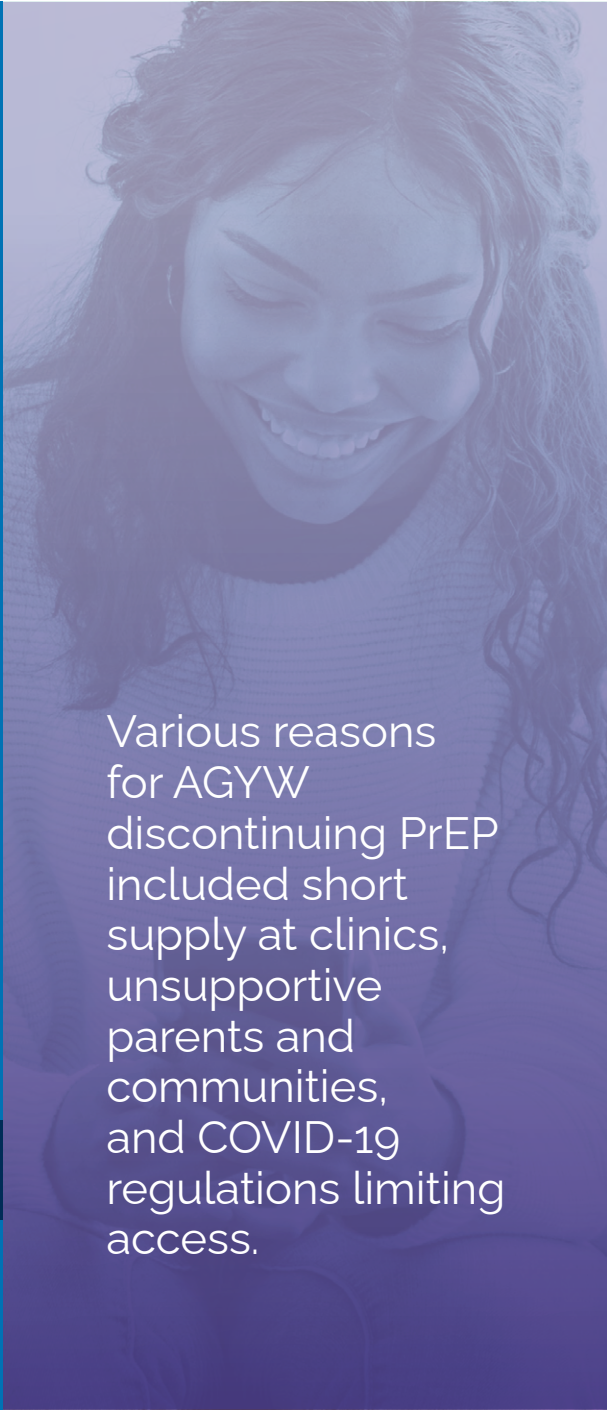
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### BACKGROUND TO THE INTERVENTION

- The Global Fund to Fight AIDS, TB and Malaria (Global Fund) provided funding for a programme that focused HIV prevention on AGYW.
- The AGYW Programme (2019–2022) offered an age-tailored combination intervention for AGYW aged 15–24 in 12 districts in South Africa characterised by high HIV prevalence.
- Combination HIV prevention programmes merge biomedical, behavioural and structural interventions for combined delivery, and have been identified as one of the key strategies for reaching the 90-90-90 targets and achieving the Sustainable Development Goal (SDG) of ending the HIV epidemic by 2030.
- In line with South Africa's National Strategic Plan for HIV, AIDS and TB, 2017–2022, which prioritises AGYW aged 15–24 for PrEP, and coinciding with the National Department of Health (NDoH) scale up and roll out plans for AGYW using National Guidelines, the AGYW programme intervention included PrEP for AGYW.
- Guided by the South African Children's Act 38 of 2005, which allowed mature adolescent girls to self-consent to PrEP as early as 12 years of age, AGYW were able to initiate onto PrEP without parental consent.

### RESEARCH OVERVIEW: THE HERSTORY<sub>2</sub> STUDY

Research activities took place in 6 sub-districts in 6 South African provinces: Klipfontein, Cape Town (Western Cape), King Cetshwayo (KwaZulu Natal), Ehlanzeni (Mpumalanga), Bojanala (North West), Nelson Mandela Bay (Eastern Cape), and Thabo Mofutsanyana/DiHlabeng (Free State). These communities are characterised by high HIV prevalence, and high rates of teenage pregnancy. Between November 2020 and March 2021 we conducted in-depth interviews with 38 individuals involved in implementing the intervention in various capacities. We purposively sampled a range of implementers, including programme managers and project coordinators, health care providers / nurses, social workers, counsellors, peer group trainers and outreach workers. Semi-structured interview topic guides were used to explore barriers and facilitators for implementation, and all aspects of intervention delivery, feasibility and acceptance. We also examined contextual issues that may have shaped the delivery of the intervention.



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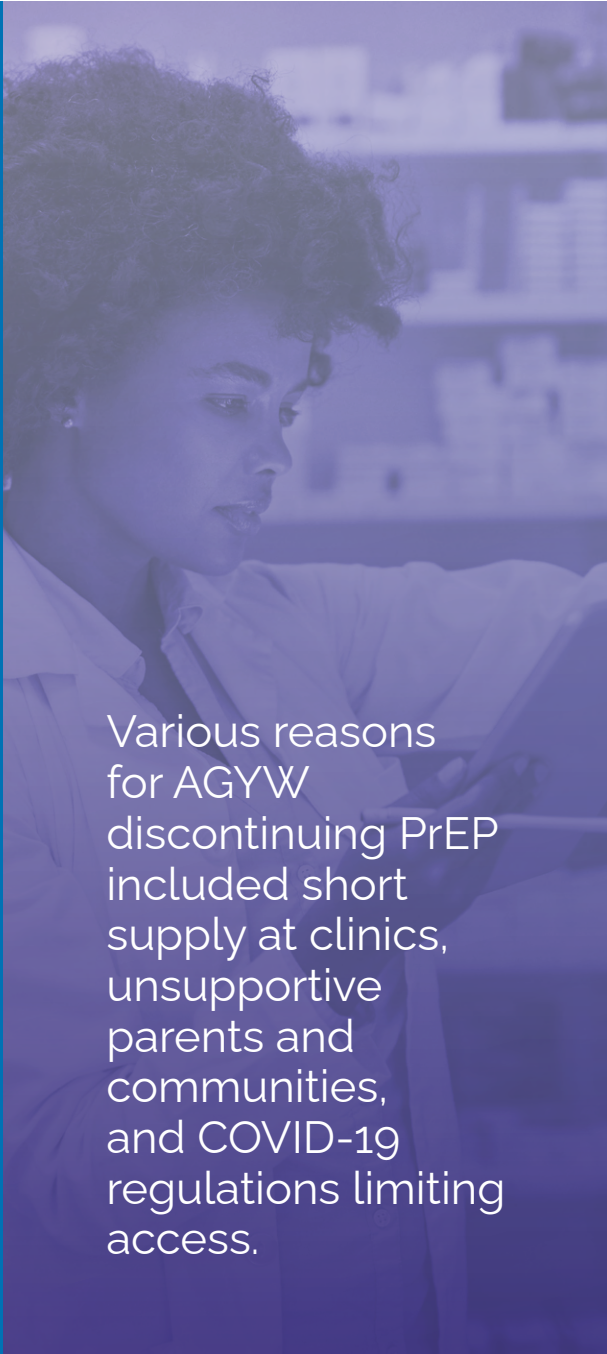
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### WHAT WE FOUND

- Several challenges associated with PrEP uptake, adherence and acceptability were described:
  - AGYW feared negative side-effects of PrEP, either from experiencing negative side-effects themselves, hearing about bad experiences from peers, or due to rumours and stories circulating
  - AGYW found it hard to stick to the daily tablet dosing regimen
  - Various reasons for AGYW discontinuing PrEP included short supply at clinics, unsupportive parents and communities, and COVID-19 regulations limiting access.
- Implementers described AGYW enthusiasm over the idea of injectable PrEP, suggesting that given their familiarity with injectable contraceptives, **AGYW would be more willing to have an injectable HIV prevention product rather than take daily oral tablets**, and that this might help to circumvent some of the issues relating to adherence and PrEP stigma.
- PrEP stigma at multiple levels emerged in our findings, falling broadly into three categories:
  1. public stigma due to perceptions of PrEP being HIV treatment rather than prevention, and linked to this
  2. anticipated stigma amongst AGYW who feared being labelled as HIV positive for taking PrEP
  3. PrEP stigma related to assumptions that PrEP users were promiscuous / "high risk."

### PrEP STIGMA

- The global framing of PrEP being targeted only to certain 'high-risk' population groups in clinical guidelines, and persistent focus on risk in the framing of PrEP, enhances perceptions of PrEP being linked to risky sex, sexual irresponsibility and promiscuity, which in turn adds another aspect to PrEP related stigma
- The South African government's categorisation of AGYW as a high-risk population that should be prioritised for PrEP delivery, may have inadvertently fuelled healthcare providers' already negative perceptions of adolescents' sexuality.



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- Findings highlighted the **critical role of parental and community acceptability of PrEP as an enabler to successful implementation.**
- Adolescents are strongly influenced by the home and family environment, and therefore social support for PrEP use, and factors operating at the household, social and community levels, are critical in the successful enrolment, retention and adherence to PrEP amongst AGYW.
- One key challenge cited by implementers related to a **lack of understanding and accurate knowledge about PrEP amongst parents and community members.** Misinformation led to resistance towards PrEP provision to AGYW.
- Linked to the importance of parental buy-in for PrEP was also the **issue of parental consent** for enrolling AGYW into the PrEP programme, described by implementers as an ethical and legal dilemma.
  - Family tensions and conflict arose when parents discovered their adolescent was taking PrEP without their knowledge, creating challenges even when legally, consent from parents was not required
  - Requiring parental/guardian consent for PrEP amongst adolescents can inhibit access and uptake for the reason that requesting consent entails disclosure of sexual activity
- Evident in our findings was also a narrative of resistance to PrEP based on mistrust fuelled by social media. Medical mistrust, encompassing a lack of trust in medical providers, the information they provide, and the medical system within which they function, is likely to be exacerbated within the context of COVID-19 vaccine hesitancy
- Similarly to parental or caregiver buy-in, **community acceptability of PrEP was a key enabler for implementation versus resistance to PrEP rollout** in communities in which community members were poorly informed around PrEP, or opposed to PrEP for moral or religious reasons. Opposition to PrEP from religious and faith leaders was a challenge.
- Findings indicate that collaboration and good working relationships between implementing organisations and public facility clinic staff can promote and enable PrEP programmes, enabling successful PrEP demand creation, provision and retention.

The South African government's categorisation of AGYW as a high-risk population that should be prioritised for PrEP delivery.


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- However, even where relationships were good, there were issues with stock-outs at the facility level, which threatened to undermine the PrEP programme.
- As with any biomedical intervention, logistics of supply chain management, including procurement and distribution, can be challenging. Implementers described how the roll-out of the PrEP programme faced various delays due to challenges in supply of PrEP through the National Department of Health, which negatively affected AGYW participation. A key challenge in community-based PrEP delivery relates to commodity supply, not only of PrEP, but also of HIV testing kits and laboratory supplies.
- Overall, implementer respondents believed that PrEP is an important and valuable tool in HIV prevention, and were excited about being part of an innovative programme.

### PrEP AND PARENTAL CONSENT

- Debates on parental consent for PrEP centre around interpretation of the South African Children's Act which makes provision for children from the age of 12 to give their own consent for medical treatment; in this case, if PrEP is interpreted as 'medical treatment', then self-consent for PrEP is permissible for persons over 12 years, if they have the mental capacity and maturity to understand the benefits, risks, social and other implications of the proposed treatment.
- Opponents to this view posit that whilst the Children's Act provides clarity on consent to most medical interventions for children under 18 years, it does not directly address the age at which adolescents might self-consent to non-specified preventive interventions such as PrEP.
- However, PrEP proponents argue that although PrEP is not expressly referred to in the Children's Act, it should be interpreted as being a form of 'medical treatment' so that it falls within the ambit of one of consent norms in the Children's Act, and therefore can be accessed independently by adolescents from the age of 12 onwards as a form of medical treatment.



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### IMPLICATIONS

#### Community Engagement and Buy-in for PrEP programmes

- Given the power that religious and faith leaders have to sway community opinions, it is critical to engage with community gatekeepers and opinion leaders in open dialogue, and provide information about and promote acceptability of new HIV prevention tools such as PrEP, in order to create a conducive environment of AGYW's successful uptake and adherence to PrEP.
- The engagement of men and boys is a critical factor in creating an enabling environment for PrEP use amongst AGYW, specifically efforts to address male perceptions that associate female PrEP use with promiscuity and mistrust.

#### Community awareness and education about PrEP

- A key aspect of increasing the availability and accessibility of PrEP to AGYW entails the expansion of education campaigns which can work towards raising community awareness around PrEP, and dispel confusion about PrEP as prevention rather than treatment.
- Community awareness campaigns to promote PrEP uptake and address resistance, misconceptions, and problematic social attitudes towards PrEP can help to dispel myths and problematic social perceptions of PrEP, and therefore address barriers to PrEP acceptability and uptake.
- Messaging needs to ensure a **positive framing of PrEP** that not only works to create interest and improve demand creation amongst AGYW themselves, but also serves to build broader community awareness, trust and support for PrEP, in order to reduce stigma associated with using antiretrovirals for prevention and foster the necessary social support for PrEP use amongst AGYW.
- To facilitate disclosure of PrEP use, and therefore positively impact uptake and adherence, programmes comprising demand creation and community education campaigns, empowerment and social support interventions, and the promotion of adolescent-friendly healthcare services are needed.
- Of critical importance is the provision of sufficient pre-counselling about how and when PrEP has sufficient protective coverage, alongside the provision of clear, accurate and simple information and infographics to AGYW, parents and communities, that illustrate concepts such as viral replication, mutation and drug resistance to make this point about the difference between antiretroviral therapy (ART), post-exposure prophylaxis (PEP) and PrEP.



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### Contextually relevant messaging and education around PrEP


- In order to address community resistance and context specific barriers and facilitators to PrEP uptake and adherence, community campaigns need to be contextually appropriate and 'culturally competent', informed by a comprehensive formative research.
- Contextually responsive and culturally appropriate interventions to shift social norms and views towards PrEP and adolescent sexuality more broadly, could be delivered through multi-level programmes offered in schools, healthcare settings, community centres and faith-based venues, and through the media by engaging trusted sources, opinion-leaders, influencers, peers and existing social networks.

### Shifting the narrative about PrEP

- Shifting the narrative surrounding PrEP, to move away from the message that PrEP is for 'high-risk' groups, 'key populations', or promiscuous individuals, but rather for anyone in the general population who wants to empower themselves by protecting themselves and taking responsibility for their sexual health would help to de-stigmatise PrEP and thereby normalise its use.
- Efforts to destigmatise PrEP and frame it as an empowering prevention tool that any responsible person can opt into at an appropriate time, could include rebranding with clear messaging and packaging to distinguish PrEP from ART, and offering PrEP alongside contraceptives, as part of an integrated broader package of SRH to AGYW, with a focus on promoting sexual health, pleasure, and intimacy.

### Making PrEP 'adolescent friendly'

- Capitalising on the power that peer influence and social support have on facilitating PrEP uptake and adherence amongst AGYW, programmes should offering platforms for PrEP users to engage with and support each other.
- Implementation strategies to roll-out PrEP to AGYW need to be combined with messaging stressing the importance of condom use, to prevent other STIs and unintended pregnancies.



Community campaigns need to be contextually appropriate and 'culturally competent', informed by a comprehensive formative research.

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- PrEP programmes aimed at AGYW need to consider the lived realities of adolescents and young people in South Africa, and take into account user preferences for drug delivery and dosing, for example offering less user-dependent HIV prevention methods such as long-acting injectable PrEP rather than oral daily tablets, or intermittent versus daily use, in order to increase acceptability and reduce barriers to uptake, retention and adherence.
- In recognising the diversity of AGYW in South Africa, living across the socio-economic spectrum and facing different daily lived realities, adherence support approaches and incentives need to be tailored and responsive to this diversity.

### Ensuring supply

- In addition to efforts to address issues relating to acceptability of PrEP, there is a need to address challenges with PrEP supply monitoring, forecasting, database management, distribution and delivery, as unreliable provision negatively impacts acceptability, uptake and retention.
- Innovative strategies are needed to mitigate supply interruptions, increase availability and access, and enhance uptake and support PrEP use continuation amongst South African AGYW
  - A differentiated model could include flexible PrEP refill schedules, and various delivery options and distribution settings in addition to standard health facilities, such as mobile clinics and community-based venues, and even courier delivery services.



### Paper that this brief is based on:

Duby, Z., Bunce, B., Fowler, C., Jonas, K., Bergh, K., Govindasamy D., Wagner C. & Mathews, C. (2022). "These Girls Have a Chance to be the Future Generation of HIV Negative": Experiences of Implementing a PrEP Programme for Adolescent Girls and Young Women in South Africa. *AIDS Behav* (2022).

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