

ORAL PrEP YOUTH DIALOGUES

SOUTH AFRICA: What AGYW really think about PrEP, HIV services and how we talk to them!



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In 2016, the National Department of Health (NDoH) of South Africa (SA) launched a phased rollout of oral pre-exposure prophylaxis (PrEP). The OPTIONS Consortium, in close collaboration with the NDoH, developed the creative concept *'We Are The Generation That Will End HIV'* and applied it to all information, education and communication (IEC) material. The creative concept aimed to generate demand for oral PrEP as an additional and acceptable HIV prevention method.

Adolescent girls and young women (AGYW) were engaged in youth dialogues held across SA to gather feedback on the concept and printed material and explore oral PrEP knowledge, barriers to testing, intent to access services and social mobilization. Fifty-nine (59) youth participated, of which 48 were AGYW, 10 young men and one a transgender woman.

BACKGROUND

IEC campaigns are one of the most common and cost-effective behavioural intervention strategies (Drysdale, 2004). Mass media campaigns constructing the image of healthy lifestyle choices can exert a significant influence on risk awareness, self-efficacy, and other behavioural predictors (Agha, 2003). IEC materials should be adapted if needed, according to subpopulation specifications and needs, and in the case of oral PrEP, this requires continuously engaging AGYW.

At the request of the NDoH, Wits Reproductive Health and HIV Institute (Wits RHI) conducted a series of youth dialogues across the country to evaluate IEC materials created for the oral PrEP rollout while also delving deeper into thoughts and opinions of young people in relation to service delivery and the rollout of oral PrEP. The youth dialogues aimed to understand whether young people identified with the central

KEY FINDINGS

- IEC materials and messaging with positive creative concepts that invoked an emotional connection with the user drove demand, stimulated interest in and encouraged uptake and continuation of oral PrEP.
- IEC materials were well-received in relation to design, colour, photographs used and font size.
- HIV testing is still feared due to the stigma associated with a positive result and myths around testing.
- Self-screening was seen as beneficial but the consequences of receiving a positive result in the absence of support and counselling was of great concern.
- Convenient services, such as mobile clinics, youth friendly clinics and oral PrEP courier delivery were seen as desirable and having potential to increase access to services.
- NGO-operated clinics and campus clinics were preferable to public healthcare facilities.
- Health services must be provided without compromising patient confidentiality or indicating the specific service being sought.

creative concept used in the IEC materials — “We Are The Generation That Will End HIV” in a heart or circular graphic and also explored whether the IEC materials could influence the decision to start and continue oral PrEP. The youth dialogues further aimed to determine: (1) knowledge of oral PrEP and HIV prevention, (2) perceived importance of HIV prevention, (3) enablers and barriers to HIV testing, (4) intent to uptake services and importance of social

mobilisation, (5) preferred service delivery modes, and (6) appropriateness of the creative concept for a youthful audience.

The outcome of these dialogues is deemed relevant for future oral PrEP programming in relation to demand creation, the development of IEC and creative communication campaigns targeted at young people and specifically AGYW in SA.

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APPROACH

Activity type

Youth dialogues were conducted in an informal semi-structured focus group discussion style. They followed a structure whereby AGYW and some young men's current knowledge was assessed in a friendly manner and then used as the basis to engage in meaningful dialogue and provide critical insights on the possible adaptations of the IEC and demand creation materials. All sessions were audio-recorded, transcribed and thematically analysed. Some responses were captured on video and cut and edited together to provide a unique glimpse into the lives, psyche and mentality of young people.

Activity sites

In close collaboration with implementing partners, OPTIONS, from August 2018 to August 2019, conducted six youth dialogues with students at university campuses and institutions of higher education across four provinces (Western Cape, Limpopo, Free State, and KwaZulu-Natal). At the start of the youth dialogues, oral PrEP was available at 12 campus clinics in seven universities, as well as through mobile outreach services.

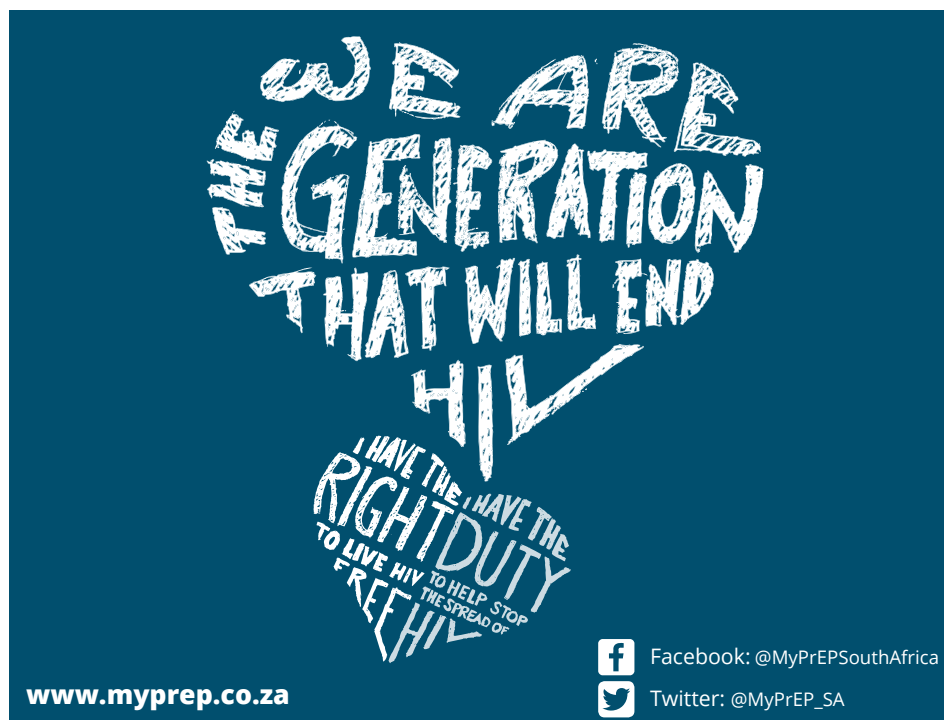
Population and sample size

Fifty-nine youth participated in the dialogues including 48 AGYW, 10 young men and one transgender woman. Each dialogue had approximately 8 to 15 participants aged 18 to 24 years and categorized as PrEP current, past or never users. The selection aimed to provide a ratio of two-thirds female and one-third male, of the 59 young people engaged; 81% were female and 19% male. The purposive selection focused on AGYW, an important target population for oral PrEP given their high HIV risk, while still acknowledging that men are important influencers in their lives.

Verbal permission was obtained from participants to partake in the dialogues and be anonymously audio recorded while written consent was obtained from participants to be video recorded with a view to later distribute the video clips.

Information collection tools

A dialogue guide featuring informal semi-structured questions and probes was used and is available on PrEPWatch at www.prepwatch.org.



The IEC materials all followed a central creative concept, referring to the heart or circular graphic that encapsulates the slogan, We Are The Generation That Will End HIV.

OBJECTIVES

Supported by the NDoH, the IEC materials were developed and created with the input of multiple partners including Wits RHI and McCann Global Health, as well as end-users. The IEC materials have been continuously adapted in accordance with feedback received and, as such, there was a need to follow a similar process of feedback with youth.

The intent of the dialogues was to facilitate market research in order to update/adapt/create IEC and demand creation materials, as well as further inform oral PrEP programming with continuous input from young people. This was achieved through the following objectives:

- **Objective 1:** Determine the current state of HIV prevention (including PrEP) knowledge among students and provide correct information where necessary for students to provide critical opinions.
- **Objective 2:** Explore students' thoughts and opinions on HIV prevention and its perceived importance, including the notion of adhering to daily medication when a person is healthy.
- **Objective 3:** Explore the enablers and barriers to HIV testing amongst students and the utility of HIV self-screening.

- **Objective 4:** Explore students' intent to uptake health services at campus clinics and what motivates this intent, including the role of IEC materials in motivating PrEP uptake and continuation.
- **Objective 5:** Determine student preference in relation to type of service delivery model for oral PrEP, as well as potential delivery channels for self-screening.
- **Objective 6:** Determine students' perceptions of the creative concept used to develop IEC materials and how it could be adapted, if necessary.

KEY FINDINGS

Key Finding 1: Don't be afraid to catch feelings!

Applying a positive creative concept, rooted in an emotional connection with the user, to IEC materials and messaging has the potential to drive demand and stimulate interest in oral PrEP, a biomedical HIV prevention product.

Participants made many positive comments on the "We Are The Generation That Will End HIV" creative concept. They reported that it gave them a sense of responsibility and hope and that it showed what could be done

if we work together — that this “fight” is for everyone. It also gave them the feeling of contributing to positive change and creating awareness around the power that a person has. One participant described it as “the best campaign ever”, while several others said that they felt happy when they first saw the design and concept. A participant said,

“Me, it makes me feel very happy because if we can look back from where we are coming from, HIV was a very serious problem. I think a whole lot of people will be happy if this thing comes to an end. So, me being part of the people that will make the disease come to an end, it really makes me feel wonderful.” (Participant 9, Limpopo Dialogue 1)

Some participants did, however, provide critical feedback on the concept. One participant expressed concern about how the concept would affect HIV-positive people and whether they would feel included in the campaign. Another young person indicated that the design was impressive but perhaps not simple enough to make sense of at first glance.

Key Finding 2: Good colour, good photos, good design

Good Colours

Participants commented on the brightness and attractive colours used in the IEC materials, referring to them as eye-catching. The bright colours used were specifically mentioned as the first thing that drew their attention.

“... uh I like the use of colours here. The colours play a very vital role in a person's mind so the minute you open the blue one it will trigger some emotion leading him or her (to be) more interested into reading the information that is spoken of. I like the colours, they play with colours...”. (Participant 9, Limpopo Dialogue 2)

Good Photos

Female participants enjoyed the use of young men in the photographs, describing the male models as charming and “boyfriend material”, noting that this “made them look”. The youth also approved the other photography, remarking that the images felt happy, inclusive and were

representative of who they are. Young people did, however, indicate a need for more photographs of young, happy South African people, particularly men, as they were underrepresented. They noted that the use of smiling models could potentially break the hold of HIV stigma. Participants observed that all the models looked different, thereby increasing the chances of a young person identifying with one of the models.

Good Design

Participants also discussed the different formats that the IEC materials were produced in. The pocketbook and posters received overwhelmingly positive feedback while the z-fold A4 brochure and fact sheet were described as having too much content and being too text heavy, respectively. The posters and pocketbook were further described as fashionable, easy-to-understand, helpful, encouraging, having information that scored figuratively as “10 out of 10” with users, vibrant and showing life. Further comments did, however, include that the font on some of the materials was too small and hard to read.

Some suggestions from youth

The majority of participants indicated that they would not necessarily change the IEC materials in any way but if they absolutely had to, suggested the following:

- Increase the variety of photographs with happy people enjoying life. They must represent the diversity of South African people.
- Include more photographs of young men.
- Reduce the amount of content.

“Include the most important information and then if they are motivated to get (oral) PrEP, that's when they can find more information to have assistance.” (Participant 9, Limpopo Dialogue 1)

- Digitalize IEC materials! Printed IEC materials carry a risk of stigma by association and may be dumped in the nearest rubbish bin. Hence, ensuring that all IEC materials are accessible online in a user-friendly and easy-to-digest manner is favorable.
- Add humour to engage youth while conveying the message and motivating for action.
- Translate the IEC materials into more South African official languages.

- Design attractive covers or first pages to better the chance of getting youth to pay attention and stay engaged.

Some participants spoke about how the IEC materials, specifically the pocketbook, helped them in their journey on oral PrEP. They pointed out that the IEC materials were a source of support that they could go back to if they were worried about something. They added that the information was clear, encouraged them to continue using oral PrEP, and reminded them why they started oral PrEP in the first place.

Inspiring Use of PrEP

Mixed thoughts emerged on whether the materials on their own would inspire one to use oral PrEP or not. Some thought they would, while others felt the chances would be higher if there was a professional on hand to further explain.

“Yes, it's yes. Because the first time I heard about that it shows by someone using it and shows that you want to stay negative” (Participant 7, Khayelitsha)

Key Finding 3: Just because it's “good for me” doesn't make it desirable.

Some young people indicated that oral PrEP continuation was not problematic. However, for those who felt that daily pill-taking was a strain, the positive messaging used in the IEC materials, rather than the benefit of oral PrEP as a biomedical HIV prevention method, was perceived as encouraging continuation.

“For me it is so difficult because I do not like taking pills, knowing very well that this is something that will keep me negative.” (Participant 13, Pietermaritzburg Dialogue 1)

Some participants felt that the IEC materials and campaign could motivate someone to consider starting and staying on oral PrEP.

“I really like this campaign. I think it really gives a sense of responsibility saying we, we'll be the ones to end HIV, not them, but so really making people more accountable and makes them want to be the ones making smart decisions and telling others about prevention methods.” (Participant 11, Khayelitsha)



Above: Dialogue participants in Pietermaritzburg having a great time discussing IEC materials.

"I think I have something to do with this where it says We Are The Generation That Will End HIV. I think I've got part; I've got certain things to do in order for it to be successful." (Participant 1, Pietermaritzburg Dialogue 1)

Other participants indicated how the design and content of the IEC materials motivated them to return for more information and consider uptake while also being a source of motivation for continuation.

"I think the content itself cos the guy who told me when I went for my HIV test, getting information for a guy sometimes is a little bit enh... but when he started telling me, I think he had a small book like this one. It was my first time hearing about such a pill so I was so interested, and I took the book home and I came back." (Participant 6, Pietermaritzburg Dialogue 1)

"I wanted to be on the pill. I feel I am at risk. That's how I feel (and the pocketbook helped me)." (Participant 6, Pietermaritzburg Dialogue 1)

"...the information here (pocketbook) can encourage me to continue using PrEP." (Participant 6, Pietermaritzburg Dialogue 1)

Participants also indicated that they had developed personal strategies to remind themselves to take their pills on a daily basis including taking their pill at the same time

as their favourite TV show, setting phone reminders and having oral PrEP buddies. One young woman indicated that she disclosed her PrEP use to her mother as a supportive measure,

"I also I told my mom that I'm taking PrEP because she is the one I'm staying with, she's my friend, we're very close." (Participant 9, Pietermaritzburg Dialogue 1)

Key Finding 4: A test is a test, scary, no matter how you spin it.

Young people highlighted that among themselves and their peers, HIV testing is still feared due to the stigma associated with a positive result, as well as myths around testing. Participants emphasized that the role of incentives for testing should not be undervalued, and that young people usually do not just volunteer to test. Other young people alluded to the fact that if an HIV positive result was truly a fear, an incentive is not enough to motivate one to test. Others indicated that youth may be inspired to test if they were to see many of their peers testing, as well as senior management from their university or college. Barriers to testing proved deeper and more far-reaching than just the result of the test. Some participants indicated a strong belief that "if you are looking for something, you will eventually find it". This statement alludes to the idea that if you regularly test for HIV, it means that you are fearful of HIV, and what you fear is what you will find. Lifelong pill-taking associated with a positive result was also seen as extremely off-putting to youth.

"... but at the end of the day, they'll still tell you [that] you want me to get tested and find out I'm dying tomorrow and after that you want me to be taking pills for the rest of my life..." (Participant 1, Limpopo Dialogue 2)

Participants also pointed to a fear of testing for HIV with a partner, which stemmed from the uncertainty of finding out that their partner was positive and the implications for the individuals involved. Participants also mentioned that some youth have never tested because they do not know their parents' (mother or father) status and fear a positive result, which is a huge barrier. Myths in relation to HIV persist and many young people believe their status is determined by who they have sexual relations with; as such, picking a "good" partner is considered safe. Other myths cited include that if a person looks healthy (not skinny), clean or educated and living a good lifestyle, the assumption is that they are HIV-negative.

"...because people don't associate certain kinds of people with certain diseases, like especially in black communities, there's certain diseases we don't associate with ourselves." (Participant 4, Limpopo Dialogue 2)

Other persisting beliefs are that pretty people cannot be HIV positive and that the virus is not a white man's disease.

Key Finding 5: HIV self-screening... maybe, maybe not.

Young people saw potential benefits in self-screening, such as privacy, in that they would not be seen testing by others and would neither be judged nor treated unfairly in public healthcare facilities.

"I say it's a good idea because most of the people are scared to go into the clinics because of how the nurses are towards patients, especially in the public hospitals because, let's say if I go there, I'm positive [and] the next morning, the whole village will know that I'm positive, that's how nurses are, especially in places where we come from." (Participant 14, Bloemfontein)

However, participants expressed concerns about the consequences of receiving a positive result in the absence of support and counselling. Some felt that an HIV test should be performed by a professional in

a healthcare setting with the possibility of confirmatory testing and follow-up counselling.

Key Finding 6: This is where and why AGYW are accessing services.

Good Service

Participants generally felt comfortable accessing health services on campus as they felt understood by the service providers there, who they described as being there for them and attending to them when they needed a service. Some participants, however, raised a few issues, which they felt still needed to be addressed, such as confidentiality, flexibility and streamlining of appointment systems.

The priority services that young people access at campus clinics, public healthcare facilities or partner-operated sites include contraceptives - especially emergency - condom procurement, STI screening and treatment, HIV testing, psychological support and treatment for "vaginal problems".

"...every next person could be carrying an infection" (Participant 13, Pietermaritzburg Dialogue 1)

Gendered Access to Healthcare

One of the dialogues delivered a heated debate on whether men access health services as much as their female

counterparts. Some felt that as the female population is larger than that of males, it should not be a concern, while others argued that men need fewer services because they do not have the same reproductive health needs as women. Another participant, however, explained that men view utilization of health services as being a sign of weakness.

"With guys, going to health centres [is seen] as weak...You find a whole lot of women in the clinic." (Participant 9, Limpopo Day 1).

Participants further highlighted that even when it comes to HIV testing, men would rather rely on their girlfriends accessing such services, arguing that if their girlfriend was healthy, it translated to them being healthy too. A participant explained:

"I feel like umm females are the ones who actually go, uses the services there and not males, is that thing of since [the girl] is protected, [the guy] is good" (Participant 7, Bloemfontein).

Participants taking part in the dialogues indicated that men would only access health services if it was an emergency:

"Maybe when [a person] get stabbed." (Participant 5, Pietermaritzburg Dialogue 2)

Improving Service Delivery

In order to improve service delivery to a young audience, participants suggested earmarking or developing clinics that are specifically for young people; this solution was mentioned with long waiting times in mind. Participants again highlighted the need for confidentiality that can be guaranteed at all times. Youth support groups were identified as a mechanism that could motivate youth to take their health more seriously. Participants further mentioned that an important issue that must be addressed is the segregation of different services which stigmatises those accessing specific services, in that, people are easily identifiable by which queue they join in a facility.

HIV treatment, family planning, mental health. "HIV positive people that side, go to [my] right... aikho right" (it's not right)..." (Participant 1, Khayelitsha)

Key Finding 7: Public healthcare facilities... only if I have to!

Young people prefer accessing services through NGO-operated and campus clinics but these do not always provide comprehensive service delivery, so youth still need to access care at public facilities. Attitudes from healthcare providers were mentioned as a barrier to accessing services at public healthcare facilities. Participants spoke of being reprimanded and judged when they had lost their clinic card or had defaulted on medication. An example was mentioned of a young pregnant woman who was turned away and denied services because she had lost her clinic card.

"And we have, we all have irights (rights)? So, if you don't, you didn't do early bookings, you went, you won't be served, why not? They will ask where is your book, liphi icard loku bookisha (where is your medical card) sisi (sister), aikho right (it's not right), ngoku ideath rate yabantwana iya increase (now the death rate for kids is increasing), then you can give birth under a tree, whatever you see" (Participant 1, Khayelitsha)



Above: Dialogue participants in Cape Town enjoyed knowing that their input would guide further discussion on PrEP rollout in South Africa.



Above: Collage of IEC materials used for the launch of oral PrEP

The long queues and waiting periods to engage with a healthcare provider were also listed as off-putting factors:

"If you get there around 1 o'clock, you can be there until 4 [then] they say they're still on lunch." (Participant 1, Khayelitsha).

Examples of services that are unavailable at campus and NGO clinics include obstetric care, treatment for minor ailments and common flu or cold. Participants also mentioned that unlike campus and NGO clinics, public healthcare facilities often provide information on TB and HIV. Some youth who accessed private facilities said they feel "robbed" of the information that is available in public settings:

"I just also feel like now that I mention that I don't go to public clinics, public hospitals or public anything, I really feel like [we get] a lot of attention by all your TB/HIV centres, your FHI360 [centres], all these centres they just put all their focus on public sectors, public hospitals public clinics and then when we who go to private hospitals, [we] are robbed of this information [of these specific posters] because there's minimal to no communication or anything about these things in private sectors." (Participant 9, Pietermaritzburg Dialogue 2)

Key Finding 8: Don't compromise on confidentiality.

Young people require a variety of services, including psychological support, that can be offered without compromising their confidentiality or indicating the specific service they are accessing. In many parts of the country, people accessing services at public healthcare facilities are made to join specific queues for different services such as family planning or HIV treatment and hence those around them know what service they are seeking. Participants were concerned that this was compromising their confidentiality, which was seen as a barrier to accessing services within public healthcare facilities.

"Um, and we've got that stigma. If you saw your neighbor there... Yeah, she's going to tell my mom that I was here." (Participant 1, Khayelitsha).

Participants stressed that providing services from a central point could not only maintain confidentiality but also reduce the barriers to services at public healthcare facilities.

RECOMMENDATIONS

The following recommendations are shared in relation to furthering oral PrEP rollout in SA:

1. Considerations for oral PrEP campaign – development, implementation and messaging

Be aspirational

- Positive and desirable designs need to be paired with empowering messaging to make HIV prevention desirable! HIV prevention campaigns compete with lifestyle products such as Nike and Coca Cola, and therefore must be developed to the same standard.
- HIV treatment and prevention campaigns must focus on an empowered and positive lifestyle which may motivate for oral PrEP continuation.

Produce attractive materials

- Bright colours and vibrant photographs communicate happiness and are attractive to young people. Photographs are essential and should include a balance of men and women of all races and cultures.
- Printed IEC materials should mimic online formats such as those used for social media, which are compact with bitesize pieces of information that can be processed at a glance.



Above: Collage of IEC and online materials adapted for use with AGYW and youth audiences.

Be inclusive

- HIV positive people should be included in HIV prevention communication campaigns advocating for HIV prevention.
- Campaigns focused on targeting heterosexual men should be implemented. Additionally, men should be included in campaigns targeting AGYW.
- Communication campaigns need to be developed with deeper and wider market infiltration in mind. More channels and tactics should be used to reach a greater audience, such as social media, television, radio, websites and other mass media tactics.

Debunk myths and tackling stigma & discrimination

- HIV prevention campaigns should combat myths that could compromise the uptake of prevention methods.
- Stigma and discrimination related to HIV needs to be tackled head on. Seeking both prevention and treatment must be seen as a bold and “cool” move and therefore encouraged.

- Healthcare facilities need to reconsider the system of queuing people according to the services being sought as this immediately identifies them as being sexually active or HIV positive.
- Public healthcare campaigns should be rolled out nationally. They must be inclusive and developed to reach all population groups, as well as highlight the benefits of the product or service for each group.

2. Considerations for HIV prevention, care and treatment and sexual and reproductive health (SRH) service delivery to young people

Considerations for service delivery

- Overhauling the health system for smoother operations, digital record keeping to speed up client care times and integration of services may reduce barriers for young people to access services.
- Integration of oral PrEP into other health services is essential to ensure young people, especially AGYW, are exposed to the benefits of oral PrEP.

- Positive public healthcare provider attitudes are essential to encouraging uptake of services by youth. Creating a welcoming and non-judgmental environment, understanding the challenges faced by youth, acknowledging their rights and respecting their privacy may encourage access to services.
- Ensuring positive and empowered messaging used in campaigns is carried through to healthcare facilities. Healthcare providers must be seen as an integral part of any communication campaign and encouraged to be spokespeople.
- Involving well-known or respected people from the community (teachers, politicians, religious leaders, youth leaders) to take part in HIV testing campaigns and drives may inspire young people to test as it will no longer be seen as a fearful and stigmatizing action.
- HIV self-screening could be an option for some but not all. The counselling support that aligns with such a screening option should be promoted.

CONCLUSIONS

Positive emotional communication paired with convenient and supportive services as well as the reward of “being part of something bigger than myself” resonates with youth. Communication across digital platforms is valued; in response, the following platforms have been established: www.myprep.co.za and @myPrEP_SouthAfrica on social media.



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Above: Throughout the dialogues young men were proud to be a part of the discussion and stand as advocates for the SRH rights of AGYW.

Left: Young people in Bloemfontein sacrificed a Saturday to share their thoughts, advice and opinions.