



USAID DISCOVER-HEALTH

TECHNICAL UPDATE: USING HUMAN-CENTERED DESIGN TO BUILD ACCEPTANCE FOR PrEP INTRODUCTION IN ZAMBIA

Key results through January 2020:

- **12,557** clients ever enrolled on PrEP
- **288** providers trained
- **228** PrEP service sites, including all USAID DISCOVER-Health supported facilities, 24 DREAMS centers and 5 correctional facilities

BACKGROUND

In November 2015, the World Health Organization (WHO) recommended that all people at substantial risk of contracting HIV be given the opportunity to take a daily antiretroviral pill for prevention. The recommendation came after clinical trials showed the effectiveness of pre-exposure prophylaxis (PrEP), when taken as directed.

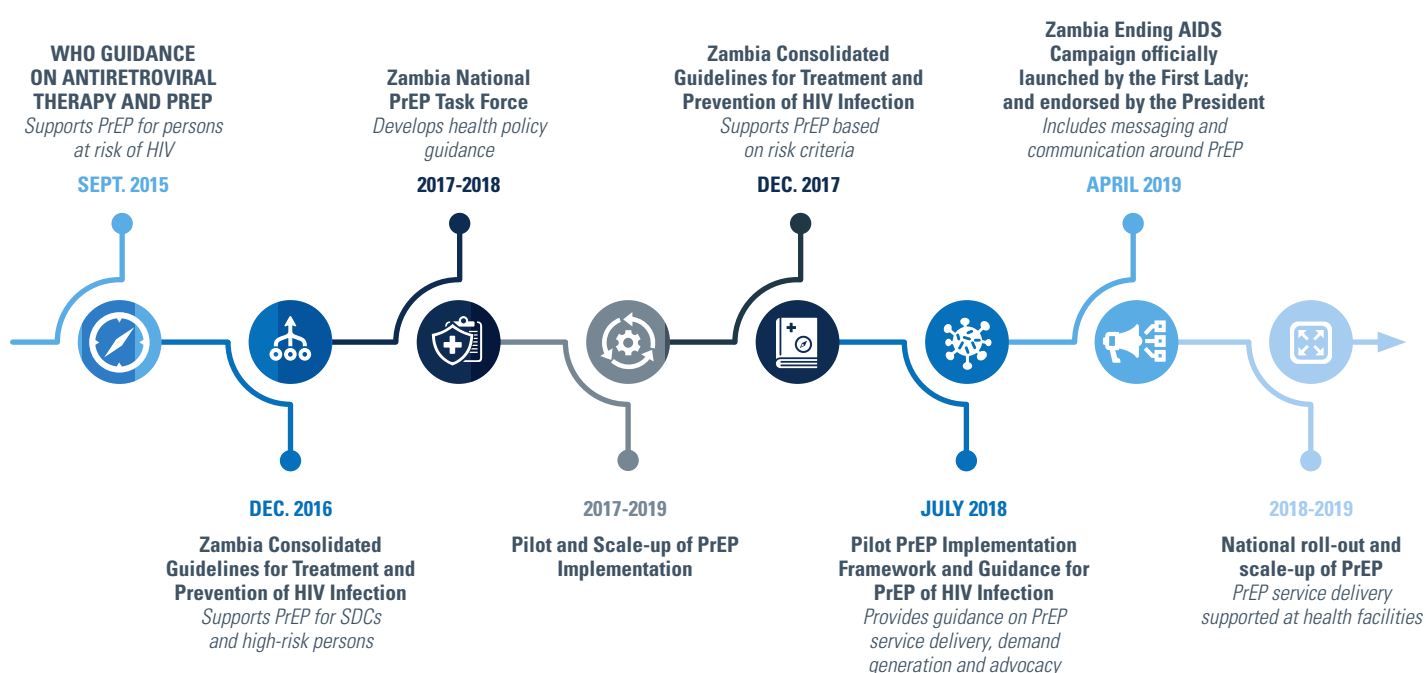
WHO's definition of those at substantial risk may include members of key populations (KPs) and priority populations (PPs) groups that are disproportionately affected by HIV. As countries that have rolled out PrEP have shown, these often include adolescent girls and young women (AGYW), HIV negative individuals in serodiscordant relationships, men who have sex with men (MSM), and female sex workers (FSWs). Each group has its own unique attitudes and barriers to PrEP. It is critical to understand and address these concerns of end users, both clients and providers, at all stages of planning and implementation for social behavior change (SBC) activities. This ensures the successful introduction, rollout, and maintenance of the PrEP program.

In Zambia, PrEP was introduced as a new intervention in 2018. This technical update describes how JSI Research & Training Institute, Inc. (JSI), through the USAID DISCOVER-Health Project made possible by the support of the American People through the United States Agency for International Development, used a human-centered design (HCD) approach to engage members of high-risk communities. Based on the meaningful involvement and input from these end users, JSI supported the rapid expansion of PrEP, delivering it to those who need it most.



PrEP IN ZAMBIA

Zambia has made great progress in its rigorous program for achieving HIV epidemic control through a range of successful high-impact interventions. With the country on the brink of achieving HIV epidemic control in 2020, overall HIV prevalence remains high at 12.1%, indicating the need to strengthen HIV prevention in addition to other interventions. In 2016, Zambia adopted and incorporated the recommendation to offer PrEP to people who are, or self-select as being, at substantial risk of acquiring HIV,¹ including KPs, in the Zambia Consolidated Guidelines for Treatment and Prevention of HIV Infection.² The guidelines recommend treatment regimens, including Gilead's Truvada and generic versions. Policy and thought leadership came from a National PrEP Task Force to steer the development of the National PrEP Framework under the leadership of the Ministry of Health (MOH) and the National HIV/AIDS/STI/TB Council (NAC). Task force members led by MOH and NAC include other government entities; donor agencies including USAID, the Center for Disease Control, and the Department of Defence; UN agencies including the WHO and the Joint United Nations Programme on HIV/AIDS (UNAIDS); U.S. President's Emergency Plan for AIDS Relief (PEPFAR) implementing partners, including JSI; and civil society organizations.



USAID DISCOVER-HEALTH IN ZAMBIA

At the national level, USAID DISCOVER-Health continues to support the introduction of PrEP by leveraging its SBC technical capacities to develop media campaigns promoting PrEP uptake and adherence. Taking this as an opportunity to look at HIV prevention communication holistically, the Project broadened the focus of its 2018 HCD study beyond PrEP, acknowledging the vacuum in HIV prevention communication in Zambia. The study sought to understand the knowledge, beliefs, and attitudes of end users of towards various HIV prevention products, including their understanding of HIV risk and factors, and barriers and facilitators to their interaction with the health system and health workers when accessing the HIV prevention products and services.

¹Substantial risk for HIV infection is defined as engaging in one or more of the following activities within the last six months: Vaginal/anal intercourse without condoms with more than one partner; sexually active with a partner who is known to be HIV-positive or at substantial risk of being HIV-positive; sexually active with an HIV-positive partner who is not on effective treatment (defined as on ART for > 6 months and virally suppressed); history of sexually transmitted infection; history of using post-exposure prophylaxis; sharing injection material or equipment.

²Ministry of Health and Social Services Directorate of Special Programmes, National Strategic Framework for HIV and AIDS Response in Zambia 2017/18 to 2021/22.

These, and other activities (see Annex A for details), gave JSI a robust understanding of the facilitators and barriers to PrEP use in Zambia. In 2018, JSI was one of the first implementing partners, mandated by the Zambian government, to roll out PrEP nationally. The Project employed its unique hub-and-spoke model, and collaborated with other implementers including the DREAMS (Determined, Resilient, Empowered, AIDS-free, Mentored and SAFE) program to provide PrEP to at-risk AGYW and the USAID Open Doors program to provide PrEP to KPs. JSI rolled out PrEP in 204 project facilities and 17 DREAMS sites in 2018. As of January 2020, DISCOVER-Health had expanded PrEP into 233 facilities, five correctional facilities, and 24 DREAMS sites.

HUMAN-CENTERED DESIGN: WELCOMING USERS' PERSPECTIVES

HCD is a design thinking approach that creates solutions by eliciting the perspectives of end users, throughout all steps of the problem-solving process. HCD's value lies in several of its main elements: empathy—understanding the expressed and latent needs of the target audience to design appropriate solutions for them; multidisciplinary collaboration with various stakeholders; and rapid prototyping to test several ideas and select the best ones to input into the designated strategy. To ground the PrEP work within an HCD framework, JSI started with a question: **How can we design a campaign that understands Zambians and what makes them use HIV prevention products like PrEP?**

JSI engaged Media 365, a Zambian business, for its expertise in HCD, campaign design, and demand creation. Together, JSI and Media 365 designed a study protocol, including question guides and facilitator manuals, and collected and analyzed existing data and baselines studies, where available. Existing PrEP data was found to be scanty and insufficient to answer the main study question, so in addition to the literature review, JSI collected data using focus group discussions and key informant interviews. JSI's HCD approach built in inclusiveness. It brought in all possible end users, including groups whose members are often marginalized—serodiscordant couples, FSWs, AGYW—along with health care workers (HCWs). From March to April 2018, JSI conducted key informant interviews and focus group discussions with various stakeholders, focusing on four themes:

1. HIV risk perceptions
2. HIV and PrEP knowledge
3. HIV and PrEP attitudes
4. PrEP use (see Table 1).

JSI also conducted observations and participatory research, as well as journey mapping, to describe individuals' access to, and use of, PrEP through the Zambian health care system.

MOH Approval Critical to PrEP Acceptance

A key finding of the 2018 HCD study was that most of the participants had not heard about PrEP. The few who had heard about PrEP had very little access to reliable information about the intervention. Virtually all had many questions and reservations, especially in the absence of overt approval of the intervention by the MOH, which Zambians see as the most credible source of health information. It was quite clear from the study results that without explicit MOH endorsement, this highly effective HIV prevention intervention would struggle to gain acceptance and traction.

TABLE 1. SELECTED STAKEHOLDERS PERSPECTIVE ON PrEP

	HIV and Risk perceptions	HIV and PrEP knowledge	HIV and PrEP attitudes	PrEP use
DESIRED	Understand individual	Accurate and high levels of knowledge of PrEP	Trusted, open to try PrEP; favorable as an additional option for HIV prevention	Using PrEP if eligible
BARRIERS	HIV risk; need to want to protect themselves and others	Accurate and high levels of knowledge of PrEP	Trusted intervention; open to try PrEP; a favorable additional option for HIV prevention	Using PrEP if eligible
FACILITATORS	Low risk perception despite high HIV risk behaviors; trust partner to protect them	Low knowledge levels; available info too technical and difficult to understand; difficulty differentiating between ART, PEP, and PrEP; HCWs still unknowledgeable at the time	PrEP largely viewed as experimental; worried about taking an ARV and side effects; doubtful of efficacy; absence of Zambia testimonials/ case-studies compounding distrust	HCW unfamiliarity with PrEP and judgmental attitudes; too many tests and routine checks; privacy and confidentiality fears; pill burden/ fatigue; congested clinics

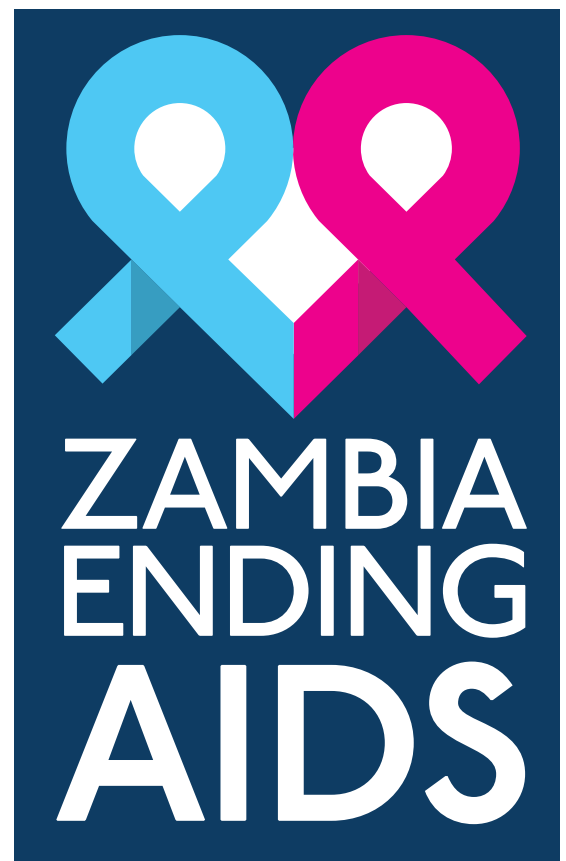
The HCD study found that most of the study participants had not heard about PrEP. Those who had heard about PrEP indicated that they had **little access to reliable information** about the intervention. Virtually all participants had many questions and reservations, especially in the absence of overt approval of the intervention by the MOH, which Zambians see as the most credible source of health information. It was quite clear from the study results in 2018 that without **explicit MOH endorsement**, this highly effective HIV prevention intervention would struggle to gain acceptance and traction. The study also illuminated a **vacuum in HIV prevention awareness campaigns**, with the result that many people, especially key groups such as AGYW aged 15-24 and males aged 20-34, do not see themselves as at risk of HIV despite engaging in high HIV risk behaviors and do not generally use HIV preventive measures.

Listening to the voices of these diverse communities helped unlock the complexities of building acceptance of, and demand for, PrEP among many end user groups. For example, stigma and discrimination affect each group's access to care differently and have profound implications for discussing and building demand for PrEP. These activities clarified the different needs and challenges of end user groups, and informed development of strategies and interventions to ensure that PrEP services would be comprehensive and sustainable.

THE “ZAMBIA ENDING AIDS” BRAND AND CAMPAIGN

As an outcome of the HCD process, between April to November 2018, JSI and Media 365 supported the MOH and NAC to develop a national HIV prevention brand and campaign: “Zambia Ending AIDS.” Launched in April 2019, it supported communication and advocacy in Zambia's efforts to achieve HIV epidemic control by 2020; sustain control beyond 2020; and move incrementally towards a future without AIDS by 2030. The campaign seeks to overcome “HIV campaign fatigue” and reignite engagement in HIV prevention, using insights from USAID DISCOVER-Health's HCD study findings and other studies. The campaign is anchored on “taking control to end AIDS; respecting self and others; making a difference” and communicating to individuals; and encouraging a collective responsibility for “ending AIDS” signifying “we are in this together!”

Project monitoring shows that the “Zambia Ending AIDS” campaign messages have reached more than 6.7 million views on social media (Facebook (<https://web.facebook.com/ZambiaEndingAIDS/>), between April and December 2019). One of the HIV prevention options that “Zambia Ending AIDS” highlights is PrEP, which is presented as a sub-campaign to provide more information about it. The sub-campaign uses messages and materials, primarily drawn from findings from JSI's HCD work, to stimulate demand creation for PrEP. As part of this package, USAID DISCOVER-Health developed a suite of information, education, and communication materials and products³ targeting end users, health care workers, and the general public, to support the rollout of PrEP nationally. USAID DISCOVER-Health metrics show that between April and September 2019, messages on radio and television have been heard more than 90 million times and seen more than 30 million times, respectively.⁴



³ These materials, including for HCWs, an app, training video; job aide; clinical steps Poster; and PrEP management information system; and for general public, a PrEP Factsheet and FAQs; animations; PrEP public service announcements (PSAs) and videos, demand generation posters; pull-ups; magazine; and both static and electronic billboards, are all available upon request.

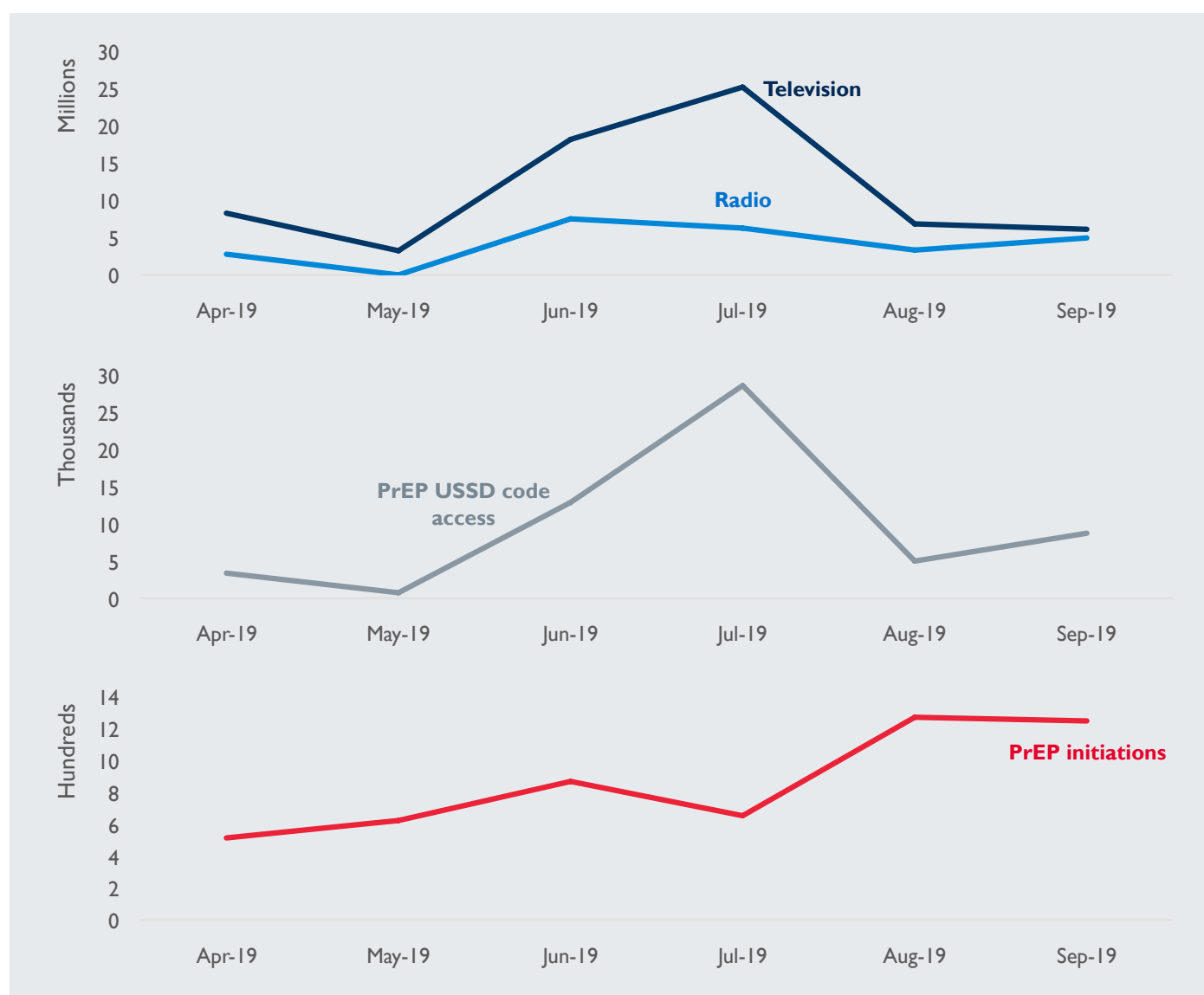
⁴ Statistics from IPSOS

PROJECT RESULTS

Using the HCD research and the visibility from the “Zambia Ending AIDS” campaign, the Project added momentum to the PrEP rollout services for eligible clients at substantial HIV risk, including activities targeting individuals in serodiscordant relationships, AGYW, KP groups, and heterosexual men. (see Graph 1)

Layering of PrEP for DREAMS AGYWs. In fiscal year (FY) 2019, USAID DISCOVER-Health increased the number of DREAMS sites offering PrEP to 22. PrEP was initially rolled out among DREAMS AGYW in FY18, and was layered onto the existing DREAMS service package as part of an integrated HIV prevention service that also included HIV testing services, family planning, and condom provision. However, there was a backlash. Parents and communities opposed girls’ use of PrEP because they had limited information about it. USAID DISCOVER-Health worked with the DREAMS partners to sensitize parents and gatekeepers. That engagement, combined with the launch of the national PrEP campaign, as part of “Zambia Ending AIDS”, made it easier for girls who needed PrEP to access the service in a more supportive environment. To date, USAID DISCOVER-Health has enrolled 2,857 AGYW ever on PrEP.

GRAPH 1. PrEP PROGRAM EXPANSION BASED ON DEMAND CREATION, INCLUDING DIGITAL SOLUTIONS



DIGITAL SOLUTIONS FOR DEMAND CREATION

9,018

appointment
reminders sent

140,933

clients accessing
PrEP USSD cell
phone portal

5,038

PrEP adherence
support messages
sent



Layering of PrEP for Key Populations. USAID DISCOVER-Health partnered with USAID Open Doors in Solwezi, Chililabombwe, Kabwe, Kapiri Mposhi, and Livingstone to layer PrEP services for KP groups which include MSM and FSW. Demand for PrEP services was created and sustained through the use of KP networks and mentors. Truck drivers were targeted and provided with PrEP services in Chililabombwe and Kapiri-Mposhi, while in Lusaka, Chibombo, and Ndola hotspots were identified and FSWs were reached with HIV prevention programs which included PrEP. To date USAID DISCOVER-Health has reached 538 MSM and 1,156 FSWs with PrEP services.

Rolling out PrEP to Zambia Correctional Service (ZCS) and Zambia Police Service (ZPS). USAID DISCOVER-Health rolled out PrEP for prison inmates in March 2019, after ZCS clearance. At Mukobeko Maximum and Mukobeko Medium correctional facilities, the Project trained inmate leaders, peer educators, cell leaders, and church leaders to sensitize inmates on PrEP. Additionally, during FY19, USAID DISCOVER-Health rolled out PrEP to the Mobile Unit of the Zambia Police Services in the Lusaka, Ndola, and Kitwe districts. The Project oriented Police Command on PrEP and trained peer mentors to mobilize fellow officers for PrEP. These police officers are highly motivated to take PrEP, and will often call from duty stations across the country for refills. As of December 2019, USAID DISCOVER-Health had 195 prison inmates on PrEP.

PrEP Program Expansion and Digital Solutions. Since PrEP is a new intervention in Zambia, its rollout required development and implementation of new information management systems and locally informed communication and advocacy activities. USAID DISCOVER-Health developed digital innovations to support access to information and client management, such as an electronic PrEP management system (including electronic adherence support). Additionally, the Project built an automated appointment reminder system in the electronic PrEP management system that sent 9,018 PrEP appointment reminders and 5,038 PrEP adherence support messages in FY19. A "missed-appointments tracker" is helping community health workers (CHWs) to keep track of clients who miss visits and follow up with them. Using a USSD short code service (USSD Short code *573*2#), anyone with any cell phone can access basic information about PrEP for free and find out the locations of PrEP facilities. A total of 140,933 people accessed information through the short code. To support HCWs and address client feedback about providers who are not informed about PrEP, USAID DISCOVER-Health also developed an app for HCWs that provides guidance on PrEP administration, including counseling skills, and is electronically linked to the PrEP management system.

LESSONS AND CHALLENGES

Through USAID DISCOVER-Health's HCD work and SBCC support to the MOH's rollout of PrEP, and through demand generation and implementation of quality PrEP services and products, the Project has learned many important lessons, including how to listen, understand, and incorporate end users' perspectives in reaching critical groups with HIV prevention, care, and treatment services:

- **Involve all stakeholders.** PrEP rollout requires a multi-sectoral partnership approach to build ownership, including government, communities, end users, and implementing partners to ensure that the new intervention is accepted, accessed, and used by clients, as well as understood and accepted by influencers and supported by authorities.
- **Incorporate community voices.** End users' perspectives must be heard and respected when designing PrEP products to ensure use of these materials and acceptance of the messaging. HCD is an ideal approach for integrating end users' views in the design, implementation, and evaluation process. Similarly, it is critical to use community involvement tools such as focus group discussions and key informant interviews.
- **Add PrEP to an integrated package of HIV and health services.** HIV service delivery in Zambia is most effective when integrated with other health services. Similarly, PrEP requires integration and coordination between community and facility—it is imperative that community-focused prevention and service-site clinical teams move as one team, building on each other's efforts, to achieve maximum results.
- **Tailored use of social media.** The “Zambia Ending AIDS” campaign illustrated the immense potential of social media for demand creation, communication, and advocacy. USAID DISCOVER-Health sees social media as a vital, powerful tool for disseminating information, especially to young people.
- **Combat misinformation.** During a PrEP program review (July 2018), USAID DISCOVER-Health learned of promulgation of myths and misinformation about PrEP. The proliferation of false information makes the use of the project's direct-to-consumer online, call-in, and mass media communication platforms even more critical. The USSD short code, in particular, helped to address misinformation by allowing people to anonymously access a reliable source of information when needed.
- **Differentiate service delivery and bring PrEP to where key and priority populations are.** USAID DISCOVER-Health increased enrollment by leveraging differentiated service delivery models to offer PrEP and other services where communities need them. This may help address mobility problems for KP groups, as well as stigma and other psychological factors that often impede access to clinic-based HIV prevention services.
- **Provide comprehensive training and periodic reviews.** Routinely providing both initial comprehensive training and periodic refresher courses for HCWs and community cadres ensures that they have, and maintain, the skills they need to conduct PrEP-related activities.
- **Carry the Health care Workers (HCWs) Along!** It is essential to train/orient the HCWs not on only technical skills, but also on developing non-judgmental attitudes. HCWs will make or break the program so equipping them to provide PrEP is worth the investment. It reduces dissonance between SBCC outreach activities and clients' actual experiences accessing PrEP services.
- **Integrate PrEP into FP/MCH programs:** Adding PrEP services to ART service points that are already see long wait times can impede both PrEP and ART programs. USAID DISCOVER-Health integrated PrEP into FP/MCH programs and were therefore able to reach at-risk AGYW (including pregnant and lactating mothers); decongest ART services; and provide one-stop-service for FP/PrEP clients in a more comfortable environment. USAID DISCOVER-Health is evaluating PrEP/FP/MCH integration to inform scale-up.

In the post-rollout PrEP program review (July 2018), USAID DISCOVER-Health carried out a post-rollout program review in July 2018 and used the findings from the review of the AGYW PrEP program to make the following adjustments:

- **Enabling environment—delay in community awareness activities.** As noted earlier, it is critical to raise awareness to ensure that a new intervention is understood and accepted by influencers, and supported by authorities. Due to an unforeseen delay in the official MOH launch (April 2019), the groundwork for the PrEP introduction could not begin and many reported a lack of community awareness activities to create a supportive environment for AGYW. USAID DISCOVER-Health responded to this challenge by providing targeted support to AGYW facing parent/guardian challenges in adhering to PrEP. At the policy level, JSI worked with other stakeholders to facilitate the PrEP launch, and supported MOH to develop a national campaign targeting the wider community.

CONCLUSION

The USAID DISCOVER-Health Project, through close collaboration with the MOH and community partners, was able to reach and provide HIV services to large numbers of at-risk and hard-to-reach populations in Zambia. The HCD approach for participatory engagement with community groups and end users led to high demand for PrEP among users and strong ownership of PrEP among HCWs. This helped to increase the uptake of PrEP, as part of HIV prevention services. The USAID DISCOVER-Health approach of creating demand for PrEP by engaging with end users is an important strategy for achieving epidemic control in Zambia.

- **Human resources—provider bias.** Program beneficiaries reported HCWs' personal biases about AGYW taking PrEP, and unfortunately, newly initiated PrEP clients did not receive support from knowledgeable and empathetic HCWs and CHWs. USAID DISCOVER-Health responded to this challenge by retraining staff and providing mentorship with an intensive focus on building their understanding about PrEP and improving skills in empathetic, interpersonal communication.
- **Human resources—provider shortage.** Zambia does not have enough clinical providers to fully support both ART and PrEP programs. USAID DISCOVER-Health responded to this challenge by training reproductive, maternal, newborn, and child health (RMNCH) staff (previously trained in Option B+) to provide PrEP, furthering the integrated approach of PrEP service provision.



ANNEX A: HCD PROCESS STAGES

Stage 1: Immersion. The first stage of the design process entails immersion, including collection and analysis of user-specific data on PrEP use in Zambia from available sources (existing evidence base). An audit of all available research, including global studies and best practices, provided by JSI, PEPFAR, and the MOH was conducted. USAID DISCOVER-Health and Media 365 conducted key informant interviews (KII) with various stakeholders, and gathered insights from key audiences using a number of methods that involve observation, ethnographic sessions, and action (participatory) research to assess knowledge, perceptions, desires, and challenges surrounding PrEP.

Stage 2: Ideation. In the ideation phase, discussions about the end users and their experiences helped to identify their needs and desires based on the research. The design workshop took place, after the journey mapping exercise and FGDs with potential end users, where discussions focused on what was learned about and from end users, identified key insights about HIV service use, including PrEP, and mapped the end user's journey to using PrEP. We also brainstormed objectives and identified strategies and interventions to ensure that the provision of PrEP is sustainable. To improve the understanding of end users, personas were developed—brief profiles that represent the key populations whose behavior we are trying to address—and journey map for each, including both risk groups and providers' perspectives, to capture discrepancies between the two. The journey map is a visual representation that illustrates the steps that end users go through to access PrEP. Journey maps were used to identify pain points (a.k.a. bottlenecks) and existing opportunities within the current delivery of HIV prevention services. The outputs of the journey mapping process provided the framework for developing communication materials and learning tools prototypes (which later became IEC, SBC, and demand generation products) through participatory brainstorming using a variety of tools including sketches and simple models. The prototypes were field-tested with a representative sample which helped obtain feedback on and refine the prototypes, and to continue learning about the product/service users. This phase is an iterative process in which quick prototype samples were made for end user first impressions and detailed feedback.

Stage 3: Creation and Implementation. During this stage, based on the feedback from the field-tests and input from relevant stakeholders, USAID DISCOVER-Health refined and obtained approval for the prototypes.

Stage 4: Feedback, Evaluation and Reporting. USAID DISCOVER-Health continues to implement PrEP activities, as well as other prevention priorities from the “Zambia Ending AIDS” campaign, regularly evaluating outcomes against objectives and making changes as necessary.

What We Heard: Barriers to PrEP

- Young men were quite willing but felt it would be challenging, due to a lack of privacy at home and parents going through their belongings.
- AGYW were willing, so they could have more choice and control, but had concerns about remembering to take it daily and where to keep it.

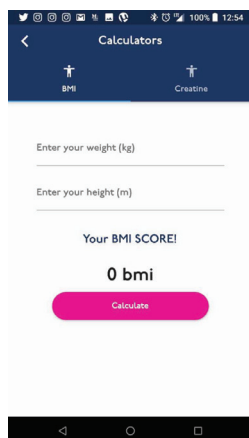
What We Heard: Facilitators to PrEP

- People living with HIV welcomed it and said they would encourage partners to use it.
- For serodiscordant couples, the female non-reactive partner was more willing and more likely to be on PrEP than the male non-reactive partner.
- For AGYW, PrEP offered the one option for one to exercise control over their own HIV prevention.
- For FSWs, PrEP would be a good way of protecting themselves, especially for clients that didn't want to use protection.
- For older men, PrEP use was motivated by the desire for “live sex.”

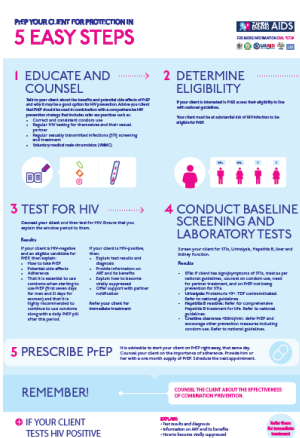
ANNEX B: HCW JOB AIDES AND DEMAND CREATION TOOLS



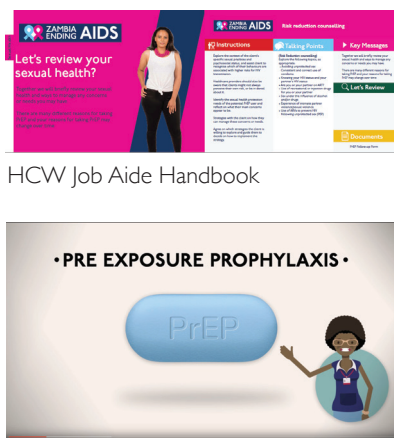
HEALTHCARE WORKER TOOLS



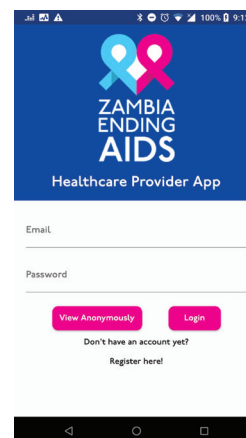
Calculator App



HCW PrEP 5 Easy Steps Poster

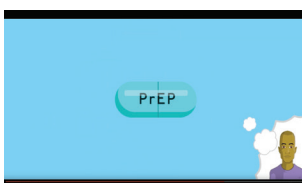


HCW PrEP Video

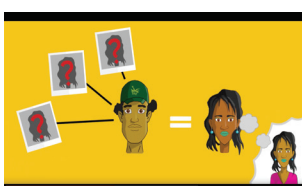


Healthcare Provider App

TOOLS TARGETING YOUNG PEOPLE



How to use PrEP video



Who is high risk video



How to use PrEP Video



Website Ad



Facebook



Website Banner

Acknowledgements:

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