

Improving the PrEP Continuum of Care Among Key Populations in Sub-Saharan Africa: A Public Health Imperative



TECHNICAL BRIEF



Community members gather in Harare, courtesy of Gays and Lesbians of Zimbabwe (GALZ), 2019

This technical brief is intended for key population advocates, community-based organizations, HIV and healthcare service providers, local and international program implementers, and national public health stakeholders. It seeks to provide a framework for effective engagement of key populations (KP) in the development of technical briefs that can be applied on a global scale. More importantly, it seeks to provide an update on HIV and PrEP Continuum of Care in Sub-Saharan Africa, share current strategies to address barriers, share information on facilitators to improve outcomes in the PrEP continuum of care, and present community-led recommendations to advance HIV prevention and care in the region.

ACKNOWLEDGMENTS

The **Improving the PrEP Continuum of Care among Key Populations in Sub-Saharan Africa: A Public Health Imperative** brief was prepared for the Key Populations Empowerment and Leadership Program (KELP), an initiative of MPact Global Action for Gay Men's Health and Rights. We would like to thank the KELP Advisory Panel (KAP) members for their feedback and support.

Recommended Citation

Improving the PrEP Continuum of Care among Key Populations in Sub-Saharan Africa: A Public Health Imperative. MPact Global Action, 2021.

Additional Acknowledgments

This publication was developed with significant contributions from a wide range of community stakeholders, including in-country KP community members impacted by HIV. We would also like to acknowledge the contribution of public health experts, including clinicians and researchers. KAP members represent KP communities in Nigeria, Kenya, Malawi, Zimbabwe, Ivory Coast, Eswatini, Namibia, Mozambique, and Tanzania.

INTRODUCTION

Key populations – gay, bisexual, and other men who have sex with men; people who use drugs; sex workers; and transgender people – are disproportionately affected by HIV in all countries as a result of social and structural barriers that impact local HIV responses and exacerbate inequities and disparities. For example, criminalization of some or all aspects of sex work in most countries in the world is a major barrier to HIV and healthcare services access for sex workers.^[1] These four key populations account for about half of reported HIV transmissions around the world each year. In some parts of Asia and Europe, they account for almost two-thirds of reported transmissions. In sub-Saharan African countries with more generalized epidemics, concentrated epidemics among key populations comprise a high share of annual HIV transmissions, for instance 34% in Kenya and 37% in Nigeria.^[2]

Existing social and structural conditions have also been attributed to the high incidence and prevalence of HIV in sub-Saharan Africa. Data from 46 countries in the region show a positive correlation between HIV prevalence and income disparity.^[3] In addition, intersecting forms of discrimination, stigma, and violence towards key populations, including transgender women, continue to drive the HIV epidemic. For example, in eight countries, 33% of transgender women said they had been physically attacked at some point, and 28% had been raped.^[4] These structural factors serve as barriers to access to comprehensive HIV care. The ongoing COVID-19 pandemic has also seriously impacted local HIV responses and exacerbated health disparities impacting key populations in sub-Saharan Africa. A recent UNAIDS report found that a six-month complete disruption in HIV treatment could cause more than 500,000 additional deaths in sub-Saharan Africa over the next year (2020–2021), bringing the region back to 2008 AIDS mortality levels. Even a 20% disruption could cause an additional 110,000 deaths.^[5]



ITPC & MPact present a workshop on PrEP in Johannesburg, South Africa, 2019

Comprehensive approaches to HIV prevention and care are urgently needed. Pre-exposure prophylaxis (PrEP) could help advance HIV prevention efforts and improve progress towards the 90–90–90 targets. In particular, the PrEP continuum could serve as frameworks for uptake in sub-Saharan Africa. The PrEP continuum includes (1) the identification of those at risk for HIV (eligibility); (2) awareness of and intention to use PrEP; (3) access to health care (especially a PrEP provider, STI screening, lab access); (4) receiving a PrEP prescription; and (5) adhering to PrEP use as prescribed.

Purpose of this Technical Brief

The HIV epidemic continues to disproportionately impact gay and bisexual men, and other men who have sex with men; people who use drugs; sex workers; and transgender people in sub-Saharan Africa. Strategies to promote HIV biomedical prevention tools, including PrEP, are needed in order to address the epidemic. The ongoing COVID-19 pandemic has led to new HIV prevention and treatment challenges, including limitations on access to care, lower levels of community resources, and weakened government responses to local public health priorities. This issue brief aims to highlight a set of challenges impacting the uptake of PrEP in sub-Saharan Africa as well as evidence-based strategies to improve gaps in the PrEP continuum of care. Specifically, it will:

1. Outline critical in-country barriers to PrEP uptake, including challenges with access to PrEP as a prevention tool.
2. Discuss innovative approaches that could work in sub-Saharan Africa, including peer-navigation, mobile technologies, advocacy efforts at multiple levels, and community-based participatory research approaches.
3. Propose a plan of action to move HIV prevention forward through biobehavioral approaches in sub-Saharan Africa.
4. Provide a framework for effective engagement of KPs in the development of technical briefs that can be used globally.

Sources of Information

To prepare this brief, we used a multi-pronged strategy that included 1) review of the literature and creation of a resource library of PrEP programs in project countries, 2) KEMP PrEP in-country survey data from 10 KEMP advisory group members from Ivory Coast, Kenya, Namibia, Eswatini, Malawi, Nigeria, and Zimbabwe, 3) online focus group with 10 members of the KEMP advisory group, and 4) analysis of the data gathered from the focus group and quantitative survey.

The review of the literature was guided by the PRISMA guidelines.^{[3][4]} The review synthesized the peer-reviewed literature as well as the gray literature (e.g., online programs, social media campaigns) on PrEP strategies currently being used in the countries identified. A comprehensive database search on EBSCOHOST was conducted with search terms including “PrEP,”



Participants at workshop in Johannesburg, South Africa share best practices for role-out and scale-up of PrEP Interventions. 2019

“Sub-Saharan African,” “PrEP Continuum of Care,” and “HIV prevention.” This methodology ensured key recommendations of this technical brief were guided by robust research methods.

We also analyzed KELP PrEP in-country surveys and synthesized quantitative data to inform this technical brief. The data were integrated in the results and recommendations sections of the brief. Given the lack of enough data on PrEP in the selected countries, the recommendations also include a call for mixed-methods studies and longitudinal studies on PrEP continuum of care among key populations. Further, guided by the nominal group technique,^[5, 6] MPact collaborators facilitated a focus group with the KELP advisory group members. Nominal group technique is defined as a method for group brainstorming that encourages contributions from everyone and facilitates quick agreement on the relative importance of issues, problems, or solutions.^[6] A bilingual and bicultural translator facilitated the discussion for monolingual French speakers.

Overall, the methods used through the triangulation of quantitative and qualitative data^[7] and the consultation and expertise of healthcare providers, including PrEP providers and community stakeholders, ensured that these recommendations were grounded in evidence, could be implemented in selected countries, and that the techniques can be extrapolated to other regions. Unique to this brief is the inclusion of voices, experiences, and solutions presented by key populations in sub-Saharan countries.

PrEP CONTINUUM OF CARE IN SUB-SAHARAN AFRICA

KELP focus group participants were asked to provide feedback about the PrEP continuum of care. In particular, they were asked how and in what ways the continuum could be strengthened and whether or not it should be adapted to be responsive to the local context. All the participants agreed on the need to add comprehensive information to the continuum and highlighted that mere awareness about PrEP is not enough. In particular, they highlighted intersectional stigma surrounding access to care and HIV prevention and the need for comprehensive information and knowledge to address stigma. After a thorough discussion on the PrEP continuum of care, consensus was reached about the importance of integrating the impact of social and structural conditions on each step of the continuum.

CHALLENGES TO PREP UPTAKE: BARRIERS TO ACCESS

Access to PrEP in sub-Saharan Africa is a major barrier to scaling up and uptake. A mathematical modeling study in western Kenya highlighted critical implementation challenges along the prevention continuum.^[10] The study noted product availability as a determinant of long-term impact. Key recommendations included the consideration of product approval of long-acting PrEP. A recent demonstration project of PrEP in South Africa with female sex workers highlighted the barriers to PrEP uptake. While participants reported the effective use of PrEP to mitigate risk, distrust in the efficacy of PrEP affected the motivation of women to come to the clinic and to maintain use. When considering scaling up, providers should ensure appropriate messaging, branding, and relevant information. These findings are critical as a new generic version of PrEP became available in September 2020.

STRATEGIES TO ADDRESS GAPS IN PrEP CONTINUUM OF CARE

Community-based approaches

Any HIV prevention strategy impacting KP communities needs to center community empowerment, access to quality comprehensive sexual health services, and human rights protections. **Community empowerment** is the process whereby KPs are empowered and supported to address for themselves the structural constraints to health, human rights, and well-being that they face, and improve their access to services to reduce the risk of acquiring HIV.

Access to quality health care is a fundamental human right. It includes the right of KPs to appropriate and high-quality healthcare without discrimination. Healthcare providers and institutions must serve KPs based on the principles of medical ethics and the right to health.

Integrated service provision addresses multiple co-morbidities and poor social situations that many KPs experience. For example, many KPs may live with HIV, viral hepatitis, tuberculosis,

other infectious diseases, and mental health conditions. Such multiple health issues are often linked to stress arising from persistent social stigma and discrimination. Integrated services provide the opportunity for patient-centered prevention, care, and treatment for the multitude of issues affecting KPs. In addition, integrated services facilitate better communication and care. Furthermore, legislators and other government authorities should establish and enforce antidiscrimination and protective laws, derived from international human rights standards, in order to eliminate stigma, discrimination and violence faced by KPs and to reduce their vulnerability to HIV.^[11]

Specific to this technical brief, community-based participatory action research (CBPAR) is an approach that ensures community participation in research. CBPAR establishes structures for full and equal participation in research by community members (including those affected by the issues being studied), organizational representatives, and academic researchers to improve community health and well-being through multilevel action, including individual, group, community, policy, and social change.^[12, 13] CBPAR emphasizes co-learning, reciprocal transfer of expertise, and sharing of decision-making power among community members, organizational representatives, and academic researchers. These stakeholders also participate in and share control over all phases of the research process, including, assessment; problem definition; methodology selection; data collection, analysis, and interpretation; dissemination of findings; and application of the results (action).^[12]

All of the participants had an opportunity to discuss and agree on the importance and significance of community involvement in all stages of the continuum of care and significance of human rights framework to guide HIV prevention efforts in sub-Saharan Africa. To illustrate this, one participant commented “We need comprehensive information sharing, capacity building

materials, and peer to peer outreach and approaches.” Another participant expanded, “HIV literacy in the context of PrEP needs to consider more than provision of individually targeted information. There is a need to influence social norms of knowledge to reduce PrEP related stigma that will influence greater messaging. To effectively promote HIV and PrEP related messages, we need to integrate a human rights based-approach.”



A group of peer educators at Ishtar MSM discuss how to get PrEP to their community in Nairobi, Kenya. 2019.

Peer-navigation models

Peer navigation interventions have been used to improve health behaviors in a wide variety of contexts.^[14] For people living with HIV, matching patients with a peer who shares key characteristics or experiences has been shown to improve HIV knowledge and antiretroviral treatment attitudes and

to decrease substance use.^[15, 16] Peer navigation may be an effective strategy to support PrEP persistence and adherence as well.

KELP participants validated the importance of peer-navigators involvement in the PrEP continuum of care. To illustrate this, one of the participants highlighted *“Making PrEP available to all key population constituencies and allowing implementation of peer-to-peer led intervention through community-based organizations will promote PrEP and HIV prevention and acceptability for key populations.”*

New technologies

Mobile technology interventions have promise to promote uptake, adherence, and retention on PrEP. A systematic review of text messaging interventions for HIV and sexually transmitted infection (STI) prevention and treatment showed that some interventions were associated with increased HIV testing and self-reported adherence.^[17] In one study, participants who received bidirectional text messages were more than twice as likely to be adherent to PrEP compared to those who did not receive text messages. The majority of participants (88%) thought that receiving the texts was very or somewhat helpful.^[18] Further, **emerging evidence suggests that smartphone-based ecological momentary assessment and intervention (EMA/I) that respond to in-the-moment contexts and social and structural factors can improve HIV prevention and care.** A smartphone-based EMA/I, with its potential to deliver reminders, encouragement, and “just-in-time” messages, can facilitate HIV prevention services, including PrEP uptake.^[18a]

KELP participants stressed the importance of the use of existing media and social networking apps to promote information about PrEP, address issues of stigma, and promote community mobilization. One participant highlighted the need for targeted messaging and approaches, *“HIV literacy in the context of PrEP needs to consider more than provision of individually targeted information. There’s a need to influence social norms of knowledge to reduce PrEP-related stigma that will influence greater messaging. To effectively promote HIV and PrEP-related messages, we need to integrate a human right based-approach.”* Another participant highlighted the need for comprehensive marketing approaches *“We need to market all HIV prevention methods and support their cadre to take a client throughout the HIV cascade.”*

Advocacy initiatives

A recent report from MPact featured case studies of HIV PrEP advocacy initiatives led by gay men in Australia, Kenya, Ukraine, Vietnam, and Zimbabwe.^[18] For example, in Zimbabwe, GALZ, the oldest LGBT rights organization in the country, has led advocacy initiatives and monitors the provision of PrEP services for gay and bisexual men through the empowerment framework. At the end of 2017, the Ministry of Health and Child Care (MOHCC) reported that only 94 men who have sex with men were enrolled in PrEP, representing a mere three percent of total enrollment. However, since then, due to a substantial advocacy campaign conducted by GALZ and others, programmatic and financial coverage for PrEP for gay and bisexual men has grown exponentially through a US\$2 million matching funds grant from the Global Fund that began in 2019.

Biomedical advances

Event Based PrEP (2-1-1): Among gay, bisexual men and other men who have sex with men, emerging evidence from clinical research is demonstrating that different dosing strategies can be effective and provides an opportunity to offer flexibility, choice, and convenience to individuals who can benefit from PrEP and is considered by WHO in updating its guidance to countries. These new strategies have the potential to reduce the cost of drugs, to reduce pill burden and toxicity, and to improve continued PrEP usage among those who find daily pill-taking challenging. ^[19]

Long-acting PrEP: This option offers a better choice for women from KPs who either do not want to take, or struggle with to take, a daily tablet. These results do not contradict evidence showing that consistently using oral PrEP is highly effective, as has been demonstrated in several trials. However, adhering to the daily dosing schedule is important. Even short lapses in taking oral PrEP can reduce the protection from HIV acquisition. ^[20]



Participants gather at PrEP Workshop in Johannesburg, South Africa. 2019.

MOVING FORWARD

Our scoping review noted the limited research on PrEP continuum of care in sub-Saharan Africa. The comprehensive review of the literature only yielded 33 peer-reviewed studies in the region. Future studies are recommended, including mixed-methods approaches to assess barriers and facilitators to PrEP.

In addition, special attention should be given to social network analysis. Social network analysis can provide a method to understand health disparities in HIV rates and treatment access and outcomes. Social network analysis is a valuable tool to link social and structural factors to individual behaviors. Social networks provide an avenue for low cost and sustainable HIV prevention interventions that can be adapted and used with diverse populations. Social networks can be utilized as a viable approach to recruitment for HIV testing and counseling, HIV prevention interventions, and optimizing HIV medical care and medication adherence. ^[21]

Furthermore, special focus should be given to structural interventions because of the crucial role of structural drivers, including stigma and discrimination, of the HIV epidemic in sub-Saharan Africa. Structural interventions in HIV prevention and treatment address social and structural determinants by focusing on the environment and context in which individuals socialize, which contributes to health-related behaviors. ^{[21, 22] [23]} Research has documented that interventions that address the contextual factors and structures driving the epidemic are more successful than interventions that focus only on the individual. ^[24] Structural HIV interventions recognize that societal-level factors such as poverty, education, social norms, and social networking are critical

underlying drivers of the HIV epidemic. ^[25] One example of a structural intervention that has promise to address HIV prevention and treatment gaps is the use of medical legal partnerships (MLP). ^[26]

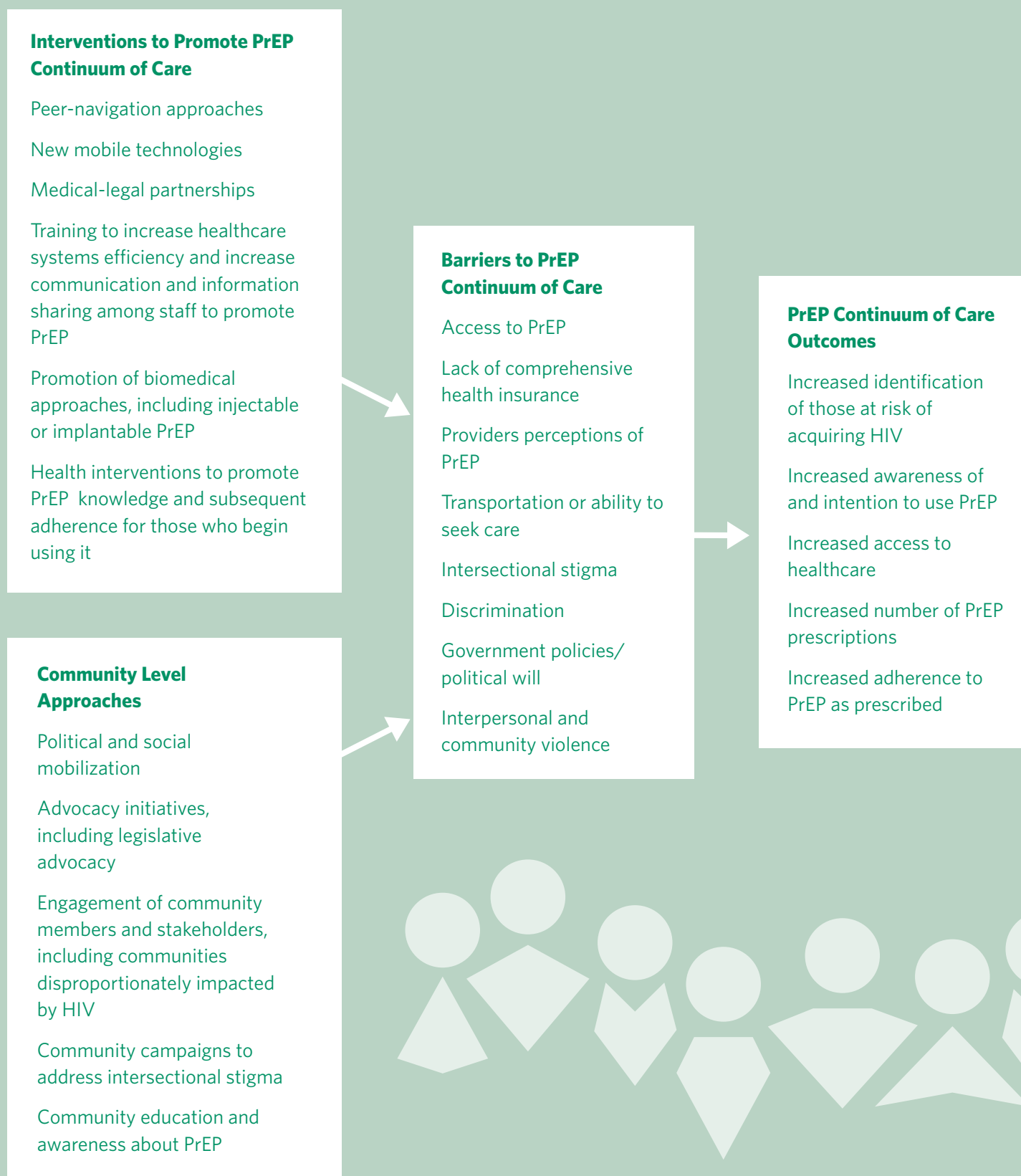
MLP is a healthcare delivery approach that integrates legal support into clinical care. ^[27-30] MLP integrates the unique expertise of lawyers and legal service providers into the healthcare setting to help clinicians, case managers, and social workers address structural problems at the root of many health inequities. Though case managers are highly qualified to coordinate medical care and other services, current professional practice norms – especially relating to the unauthorized practice of law – mean that they cannot serve as legal advocates in most instances. The integration of legal service providers into the healthcare system to serve individuals impacted by HIV has many benefits. The inclusion of a legal specialist on the healthcare team makes it more likely that issues can be identified before they rise to a level that requires legal intervention. MLP provide a holistic and interdisciplinary approach to patient care.

One country partner in Kenya is directly implementing this type of partnerships by employing lawyers and paralegals in their advocacy and service delivery model. Gender Based Violence (GBV) presents serious risks to the KP community because it affects their ability to seek and access healthcare across the continuum of HIV services. The partner organization's advocacy department is responsible for planning violence prevention, response, and redress mechanisms including conducting investigations, documentation violence and pursuing litigation. Violence and human rights violations against KPs are often fueled by the stigma and discrimination emanating from prevailing social norms. By empowering KPs to take the lead in identifying possible violence and violations when they occur, MLP interventions can prevent violence from occurring, prevent repetition of violence, respond when violence occurs, and provide follow up until full redress has been obtained and documentation is complete. Progress on MPL programming is discussed during quarterly committee meetings. Paralegals provide legal and civic education to sustain the gains and to provide legal literacy (know-your-rights) programs to community members.

As previously discussed, new biomedical approaches such as event-based PrEP and long-acting PrEP should also be evaluated for use and scale up with KP communities. While PrEP holds great promise for reducing HIV infection in high-risk groups ^[31-33], adherence to medication has become a major barrier for long-term sustainability and effectiveness. As new biomedical approaches become available, studies are needed to evaluate these alternatives to oral PrEP and develop approaches to increase uptake of these new biomedical approaches. The promotion and uptake of new biomedical tools, including longer-acting injectable or implantable PrEP, could help address some of the existing barriers and challenges to adherence.

The data gathered in preparation of this report have informed the development of a conceptual framework to promote PrEP in sub-Saharan Africa (Figure 1).

Figure 1: Conceptual Model



Appendix A. PrEP Questionnaire

PrEP Questionnaire - KAP Members

Thank you for agreeing to participate in the focus group to improve PrEP uptake in Sub-Saharan Africa

Below please find a set of questions to be completed prior to our focus group meeting. Your responses are critical as we develop community responses to promote PrEP among key populations. We look forward to "seeing you" soon! A Zoom link will be sent to you prior to the meeting.

1. How old are you?

2. Do you consider yourself to be part of any of these Key Populations (you can select more than one)?

- ☐ Gay, bisexual man or other MSM
- ☐ Sex Worker
- ☐ Person Who Uses Drugs
- ☐ Transgender Individual
- ☐ Other (please specify)

3. Where do you reside?

- ☐ Nigeria
- ☐ Kenya
- ☐ Malawi
- ☐ Zimbabwe
- ☐ Ivory Coast
- ☐ Eswatini
- ☐ Namibia
- ☐ Mozambique
- ☐ Tanzania
- ☐ Other (please specify)

4. Which of the following best describes the work you do?

- ☐ Administrator/Manager
- ☐ Program Coordinator
- ☐ Peer/Health Educator
- ☐ Physician/pharmacist
- ☐ Paralegal/legal advocate
- ☐ Regional/Country health ministry
- ☐ Substance use/harm reduction worker
- ☐ Mental health counselor
- ☐ Other (please specify)

5. The PrEP continuum includes 1. The identification of those that would most benefit from PrEP (eligibility); 2. Awareness of and intention to use PrEP; 3. Access to health care (especially a PrEP provider, STI screening and laboratory access); 4. Receiving a PrEP prescription; and 5. Adhering to PrEP use as prescribed. Which of these components are the most critical to address gaps in PrEP care in your country? Please select the **three** most applicable.

- ☐ The identification of those that would most benefit from PrEP (eligibility)
- ☐ Awareness of and intention to use PrEP
- ☐ Access to health care (especially a PrEP provider, STI screening and laboratory access)
- ☐ Receiving a PrEP prescription
- ☐ Adhering to PrEP use as prescribed
- ☐ Other (please specify)

6. Which of the following do you believe are the most common barriers that may prevent or deter key populations from using PrEP? (check all that apply)

- ☐ Lack of affordability
- ☐ Lack of health insurance
- ☐ Low accessibility
- ☐ Lack of knowledge and information among potential PrEP users
- ☐ Lack of knowledge among providers
- ☐ Concerns around safety
- ☐ Concerns around side effects
- ☐ Potential PrEP users stigma associated with taking PrEP
- ☐ Health care provider stigma related to PrEP
- ☐ Lack of policy and local commitment to HIV prevention
- ☐ Other (please specify)

7. Based on your experiences, how can we best promote PrEP and HIV prevention messages among key populations? Please describe.

Appendix B. Email Introduction and Invitation to join Focus Group

Dear KAP,

My name is Angel Fabian, Advocacy Coordinator at MPact and TA country lead for Kenya's EpiC grantees. Thank you for your patience as we continue rolling out the KELP program. We are in the process of creating a KP PrEP Technical Brief and would appreciate your direct input. As previously shared with the group, these briefs will be addressing issues of priority for our KP communities, identified either previously or throughout the course of KELP implementation. Please complete the following short survey regarding KP's experiences with PrEP services in your region/country. Please follow this link: <https://www.surveymonkey.com/r/PrEPKAPMembers> and complete by Wednesday, September 2, 2020.

We would also like to invite you to an hour Zoom discussion on the results of this survey on **Friday, September 4 at 7 am PDT** (please find your local time [here](#)) and find Zoom information below.

Thank you and please let me know if you have any questions.

Angel

Appendix C. Agenda for Focus Group

Agenda

Thank you/Brief introduction (name, pronouns, field of work, why PrEP should be framed/considered as determinant/crucial to HIV prevention?)

Angel Fabián: Overall goals/objectives of the focus group.

Angel Fabián: Proceed with questions about in-country barriers to HIV prevention and PrEP uptake. Note: We stressed the importance of hearing from everyone in the group.

Omar Martinez and Angel Fabián: Introduction to the PrEP continuum of care and facilitate a discussion about facilitators to PrEP uptake. In particular, feedback was provided on how this PrEP continuum of care should be adapted to respond to in-country barriers and facilitators to PrEP. Note: We stressed the importance of hearing from everyone in the group.

The PrEP continuum includes: 1. The **identification** of those that would most benefit from PrEP (eligibility); 2. **Awareness** of and intention to use PrEP; 3. **Access** to health care (especially a PrEP provider, STI screening and laboratory access); 4. **Receiving** a PrEP prescription; and 5. **Adhering** to PrEP use as prescribed.

Omar Martinez and Angel Fabián: Inquire about homegrown PrEP strategies, including the use of social media, mHealth technologies, local policy and community-driven initiatives, etc. Note: We stressed the importance of hearing from everyone in the group.

Omar Martinez and Angel Fabián: Wrap up/next steps. Inclusive call and invitations for collaborators to provide feedback to the technical brief.

Note: Hervette Knwihoreze, a bilingual English and French speaker, joined the focus group to provide translation to the monolingual French-speaking representatives.

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About MPact

MPact Global Action for Gay Men's Health and Rights was founded in 2006 by a group of activists concerned about the disproportionate HIV disease burden shouldered by men who have sex with men. MPact works at the intersection of sexual health and human rights and is linked to more than 120 community-based organizations in 62 countries who are leading innovative solutions to the challenges faced by gay and bisexual men around the world.

Authors:

Omar Martinez
Angel C. Fabian

Contributors:

Saurav Jung Thapa
Mohan Sundararaj
Johnny Tohme
Greg Tartaglione

Design by:

Design Action Collective

This publication is part of an eight-part series from MPact's Key Population Empowerment Leadership (KELP) program funded by FHI360 and supported by the ViiV Healthcare Positive Action Programme. KELP delivers high-quality, timely technical assistance to key population-led organizations in Nigeria, Kenya, Mozambique, Zimbabwe, Namibia, Eswatini, Cote D'Ivoire, Malawi, and Tanzania.

For more information, please contact Angel C. Fabian, Advocacy Coordinator,
afabian@mpactglobal.org.

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