PrEP – a powerful new tool for HIV prevention

Survey Results

International HIV and AIDS Alliance

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PrEP stands for pre-exposure prophylaxis, which essentially means providing HIV treatment (antiretroviral drugs) to people who are HIV negative before they are exposed to the virus, as a way to prevent them from contracting HIV. Evidence has shown that PrEP works. Currently PrEP is only available in a few countries, and not yet fully integrated into combination prevention options in all contexts.

The Alliance sees PrEP as a powerful new tool for HIV prevention that could expand the range of HIV prevention options available for people and communities. Believing that everyone should be given the possibility to choose from a range of prevention options, the Alliance wishes to work with communities to create and share knowledge on PrEP, understand if/when/how taking PrEP might be feasible, and to work together towards the end of AIDS.

The survey has been designed and reviewed by a working group across the Secretariat and some LO's already involved with PrEP from across the Alliance. The PrEP working group includes: Lucy Stackpool-Moore, Susie McLean, Matteo Cassolato, Gitau Mburu, Jane Coombes, Kate Iorpenda, Ruth Ayarza, Bangyuan Wang, Georgina Caswell, Claire Mathonsi, Robert Common, Robinah Kanyeihamba, Margret Elang, Thomas Cai, Javier Hourcade Bellocq, Jet Riparip, Robinson Cabello, Emma Aldrich and Cedric Nininahazwe.

This report outlines the initial analysis of the results from the Alliance PrEP survey. It was written by Lucy Stackpool-Moore and Cedric Nininahazwe, and reviewed by the PrEP working group.

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Executive Summary

The PrEP survey was developed by the Alliance Secretariat to ask all staff of the Secretariat and Linking Organisations (LO's) about their opinions, knowledge and local considerations about PrEP in different contexts. It was designed to get a snapshot of the ideas, perceptions, concerns and opportunities for PrEP across the Alliance.

The survey was conducted online, and was circulated to all staff and volunteers of the Alliance in June/ July 2015. The response rate was excellent, and in total 83 people responded to the survey from 24 different contexts. This included participants from LO's, regional representatives and the Alliance Secretariat in the UK.

Most participants indicated that PrEP could be a positive addition to HIV prevention efforts around the world. Some participants indicated that PrEP should be made available to everyone, and all agreed that if should be prioritised for those most vulnerable to contracting HIV. Several participants indicated that the suitability and focus of PrEP should be determined by the nature of the epidemic in different contexts.

The results indicated that the majority of participants expressed concern about the fact that there is no political will to introduce PREP because, for some, PREP is expensive and so far available with external aid what would make it less available and accessible. Others said that in their country, PREP is perceived as a waste of taxes. Lack of information and knowledge about PREP was identified as a barrier to the introduction of PREP, in addition to the fact that PREP is not yet approved by the board of pharmacy, adherence and side effects.

The main concerns expressed in relation to PrEP included cost, resistance, and fear that people won't use condoms again and that will result in the increase of STIs.

Specific areas for technical assistance were identified through the survey, which are discussed at the conclusion of the report. Overall these included support to strengthen the capacity of partners, general information on PREP such as advantages and disadvantages and the need for raise awareness campaigns.

Methodology

An online survey with 22 questions was open for 4 weeks in June/ July 2015. All staff and volunteers at the Alliance Secretariat and Linking Organisations were encouraged to respond. The online survey was in English, with the questions translated into French and Spanish as well to enable as many people as possible to complete the survey. An incentive was offered (Amazon voucher worth £25 each) and awarded to four participants. There was an excellent response rate.

In total, 83 people responded to the survey. Some participants chose not to answer all the questions, and the results are presented proportionally according to the number of responses to each of the different questions. For example if 45 people responded to a question and the others skipped it, the results are presented as a proportion of 45 rather than the total 83 who took the survey as a whole. The number of responses for each specific question included in these results is indicated for each of the proportions reported (for example n=45). This report also includes some illustrative examples of quotations from the open-ended questions in the survey. These have been quoted verbatim, and identified by the survey response number and country from which the response came from at the end of each quotation (for example 83, Haiti). Key themes from the open-ended questions were identified and responses grouped together for this report as a way to summarise some of the recurring themes.

The online survey was conducted in Survey Monkey (a free internet based survey tool) and each IP address was only enabled to complete the survey once (to prevent duplication of responses).

There was a good response from across the Alliance, and responses were received from a range of 21 specific countries and regions (Africa / Asia / Global). The highest number of responses were from Kenya (9), Africa regional (4), Indonesia (3), India (3), and Namibia (3). A detailed breakdown of the geographic distribution of responses is included in Annex 1.

Results

PrEP is already being discussed widely across the Alliance (70%, n=82), predominantly in terms of making PrEP available for MSM, sex workers, and sero-discordant couples (85%, 52% and 52% respectively; n=21). Two participants indicated that PrEP was being considered for everyone in the general population (both from Kenya).

> *"[PrEP could be] a good tool that will be able to reduce HIV prevalence."* (83, Haiti).

Context - current priorities for HIV prevention

To keep the survey about PrEP in perspective, participants were asked to identify the biggest priority for HIV prevention in their context. The main priorities identified were:

* Access to services, which included:
  - Integration of comprehensive HIV prevention with other programs such as methadone maintenance therapy, SRHR etc.
  - Comprehensive sexual and reproductive health services (including STIs) particularly for young people.
  - Scaling up efforts to reduce vertical transmission of HIV, particularly with young mothers. Provision of free services (i.e. removing cost as a barrier) for HTC, ARVs, STI treatment, PEP etc.
* Combination HIV prevention, that does not only focus on biomedical interventions and includes efforts to reduce stigma and discrimination throughout prevention approaches such as:
  - Condoms - including commodity security to prevent stockouts.
  - Social and sexual behaviour change communication, including information, education and communications tailored to meet the needs of different people including key population groups, young people, and people over aged 50.
* Funding and political commitment, so that combination HIV prevention is supported adequately with resources and government attention (e.g. in national strategic plans)
* Research, monitoring and evaluation to ensure sustained attention to the drivers of HIV, and attention to evidence based programming in all aspects of HIV response as well as continued scientific progress such as towards a vaccine.
* Reducing stigma, so that everyone (including those who are positive) accept an HIV status and to enable more people living with HIV to be reached who are not yet diagnosed or aware of their status.
* Community level interventions to support local thinking about HIV prevention and to build demand for methods and use of services.

Potential impact of PrEP

The potential positive impact of PrEP was predominantly listed as an increased range of options to enhance HIV prevention - in general, and also for specific population groups who consider themselves at high risk. Groups identified include MSM, sex workers, truckers, prisoners, sero-discordant couples, transgender people and key populations in general.

"It would add another weapon in our prevention arsenal. It could help us reduce incidence further." (25, Namibia)

"A wider mix of options can only be a good thing." (55, East Africa)

"Adds to the range of prevention options and helps people chose what works best for them." (14, South Africa)

"*[PrEP can] provide prevention technology that empower[s] the users.*" (54, Argentina)

The main potential negative effects of PrEP identified included stockouts of ARVs for people living with HIV, resistance to treatment, cost and adherence challenges.

"If we use Truvada and people become resistant what are the consequences for treatment combinations." (14, South Africa)

A few participants identified the risk of reduced risk of condom use and increase in risky sexual practices.

"Condoms [could] become a thing of the past - hence STIs will continue to rise… People would stop using condoms." (12, Asia)

Concern about a potential increase in STIs was apparent in the responses from Latin America, in particular Peru, Bolivia and Southern African responses.

Some of the comments indicated that there is some confusion about the differences between PEP and PrEP, and how it could be used. For example some participants likened PrEP to the emergency contraception pill, or for use in cases of sexual assault and gender based violence, or for the prevention of vertical transmission of HIV from a mother to her infant during pregnancy. Some participants also considered the possible application of PrEP to working with Health Care Providers, also indicating confusion between PEP and PrEP and universal precautions in provision of health care. One participant noted the potential for PrEP to be confused with a cure, and that information be carefully tailored and communicated effectively.

"[PrEP] might be viewed as cure or not be taken correctly. It would need clear communication. There might be long term morbidity issues that we are not yet aware of." (25, Namibia).

Cost of PrEP

More than two thirds of participants indicated that they thought people would be willing to pay for PrEP if it became available in their context (68%, n=44). However some responses noted that it would be difficult to get people to pay when they have been unaccustomed to paying to HIV prevention, and that some of the people most at risk of contracting HIV would not be able to afford to pay (particularly from key population groups). Many indicated that it would depend on the cost, 76% of those who thought people would be willing to pay (n=33) indicated that it would be appropriate for people to pay less than USD$20 per month for PrEP. Some participants noted that it would depend as to which population groups PrEP was being targeted for, especially given that most other HIV and STI prevention technologies are currently free of charge.

The majority of participants thought that the government should provide PrEP for free (78%, n=46). However some people indicated that this might not be realistic, given current challenges in resourcing the national HIV response.

"That will be the best choice but right now no money in National budget for HIV/AIDS." (53, Haiti)

"Currently, the government is not even able to finance ARV treatment without external support." (42, Burundi)

Others thought that there might be challenges in public opinion in regards to PrEP and who should pay.

"If the government were to provide PrEP for free there would be strong opposition in the populace against it and this would negatively impact on the advantage of PrEP." (82, Nigeria)

This was linked to notions of responsibility for some - either at the personal level or at the government level, introducing a moral dimension to the notion of who should pay for PrEP.

"It's the role of the government to provide health care." (14, South Africa)

"It is one form of prevention, others are available. People have to take some responsibility for themselves." (5, UK)

On participant indicated that cost and the availability of PrEP should be used as a deterrent, so that people do not misuse PrEP and risk STIs.

"*PrEP should not be provided to everyone because people will misuse it and instead encourage sexual behaviors."* (19, Kenya)

A few participants noted the potential long term cost-saving from investing in PrEP as part of sustained/ scaled up HIV prevention efforts.

"It is a national health response. If they drugs could prevent HIV infection, and in turn save the country millions of dollars in health expenses then yes." (80, Namibia)

One third of participants indicated that PrEP should be available free for everyone (33%, n=42), whereas some thought it should only be available to certain specific community groups such as MSM, sex workers and sero-discordant couples (all 52%), then regular partners of people living with HIV (40%) and people who use drugs (36%). Four participants thought that PrEP should not provided free of charge to anyone. Some suggested that a means adjusted sliding scale for payment (like with prescriptions in the UK), social security and/or medical insurance should cover the costs.

Prioritising PrEP for specific communities

Most participants indicated that PrEP was more suitable for some communities over others, even though many participants thought it should be available to all (16%, n=25). Of those who responded to this question, the majority identified MSM, sex workers and sero-discordant couples as the most suitable communities to receive PrEP (68%), followed by the regular partners of people living with HIV (60%), transgender people (52%), and people who use drugs (36%). Several participants indicated that the suitability and focus of PrEP should be determined by the nature of the epidemic in different contexts.

In terms of prioritisation of specific communities to receive PrEP first, the results were consistent with the responses on the suitability of PrEP for different communities. The results indicated that the majority of participants felt that MSM (75%, n=40), sex workers (63%), people in sero-discordant relationships (58%), transgender people (50%) and the regular partners of people living with HIV

(45%) should be prioritised for the rollout of PrEP. Seven participants suggested that PrEP should be prioritised for everyone (18%).

Models of service delivery

Almost all participants indicated that PrEP should be introduced as part of specialised HIV services (93%, n=27). The majority suggested that PrEP should be offered in facility-based provision of services (75%) compared with those who thought it should be provided in community-based settings such as through peer-to-peer outreach (62%) or services provided by community based healthcare workers (65%). Several participants suggested entry points for integrating PrEP with other services such as TB, SRHR, condom distribution and primary health care facilities.

Personal attitudes

The majority of participants indicated that at a personal level, assuming they were HIV negative, they would consider taking PrEP (80%, n=44). Some participants indicated that they personally would be willing to campaign against stigma and discrimination, which may create barriers for people accessing PrEP and other HIV services.

> *"As a man who worked with the Injecting Drug User and have marriage to a HIV person and already have 2 children undergo PrEP and not infected with HIV, would like such story to be recorded and publish to public which I hope would help decreased the discrimination and stigmatization in my country and drawn many infected and affected person to come out for treatment and live in normally."* (32, Malaysia)

Barriers and challenges to introducing PrEP

Some of the challenges for introducing PrEP identified included availability, access and acceptability of PrEP. The main barriers identified were cost (72%, n=29), and lack of information and political will about PrEP (55%, n=29) in terms of funding for HIV prevention as well as regulatory frameworks.

> *"I find this very relevant prevention approach. However, it can hardly be ensured in the context of a country that is not yet able to fund treatment for PLHIV on ART."* (42, Burundi)

Stigma, discrimination and criminalisation of the potential beneficiaries of PrEP were also identified as challenges within communities as well as for the creation of an enabling policy environment for PrEP (55%; n=29). Eleven responses cited organisational capacity as one of the main challenges (38%).

> "*Most [Lower Income Countries] LICs are still not able to provide ART to people whose CD4 is below 500 --there are huge resourcing -both financial and human --challenges. PrEP adds another layer of complexity especially when issues of equity are being discussed in the context of first focusing scarce resources on PLHIV and sero-discordant couples."* (23, Sub Saharan Africa)

Some participants identified that because PrEP is not yet available advocacy and other initial efforts need to be in place to ensure the combination HIV prevention is sustained and also prepared to incorporate PrEP. This included concern for adequate funding for and access to ARVs.

> *"PrEP is not accessible. advocacy efforts are required to ensure that Prep is included as a national prevention strategy."* (64, Botswana)

Others cautioned against the Alliance getting too caught up in the "hype" currently generated around PrEP and the risk of losing focus on other aspects of community engagement in HIV responses and broader social determinants of health.

"I hope the Alliance doesn't get caught up in all the hype around PrEP... and treatment as prevention... without remaining critically vigilant about some of the potential risks and hazards in undermining the hard-won gains to address social inequalities and wider structural determinants of health." (45, UK)

Technical support needs identified if PrEP were to become available

Many different responses were given to this question which have been grouped into categories and summarised here:

* Training - in basic information about PrEP (including history and milestones), WHO and other guidelines, strategies for demand creation and community mobilisation, administration of PrEP, client management and support.
* Supply chain - including storage, transport, commodities, lab monitoring and surveillance of effectiveness.
* Communications - for community mobilisation and demand creation for PrEP (in general, and also tailored to specific key population groups), as well as to respond to those who may object to ARVs being used in this way; IEC materials; help with media engagement to influence public debates on PrEP; comprehensive sexuality education in schools and HIV prevention.
* Clinical information and training - about resistance, adherence, oral/ vaginal/ rectal intake of PrEP.
* Research capacity development - to monitor the effectiveness of PrEP, evaluating outreach models and using evidence based advocacy to scale the intervention, to be informed by the results from demonstration projects, risk assessments.

Recommendations for the Alliance

The responses to this survey indicate a generally positive perception of the potential impact for the addition of PrEP to combination prevention efforts to response to HIV around the world. Concerns were raised about the cost, sustainability and appropriateness of PrEP in contexts where there is limited or inadequate access to ART for people living with HIV.

Responding to the survey results, and to the areas for technical support identified by the participants, it is recommended that the Alliance Secretariat should:

- Provide more information about PrEP (to avoid confusion with PEP and other aspects of combination HIV prevention).
- Convene acceptability and feasibility community discussions with sex workers, young people and other key population groups whose attitudes and values have not been adequately considered in the existing research (that has focused predominantly on MSM).
- Respond to and provide the technical support needs identified.
- Stay abreast of international developments and latest research, funding opportunities and political momentum building around PrEP while maintaining focus on the broader context of community engagement in all aspects of the response to HIV and ending AIDS together.
- Maintain thought-leadership and critical discussions that connect staff at the Secretariat and LOs working on PrEP, through specific projects, proposals and community engagement.

Thank you to the PrEP working group for the initiative to undertake this survey and generate these recommendations for future informing proposal development and Alliance programming with PrEP.

Annex 1: Breakdown of country/ regional responses

Africa regional - 4
Asia regional - 1
Argentina - 1
Bolivia - 2
Botswana - 1
Burundi - 1
China - 1
DR Congo - 1
Equador - 2
Haiti - 2
India - 3
Indonesia - 3
Kenya - 9
Malaysia - 1
Mexico - 2
Namibia - 3
Nigeria - 1
Peru - 1
Senegal - 2
Secretariat (global) - 3
South Africa - 1
UK - 15
Vietnam - 1
Zimbabwe – 1
Not specified – 21

Total responses = 83