INCREASING ACCESS TO PrEP IN LATIN AMERICA

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Spanish translation in progress

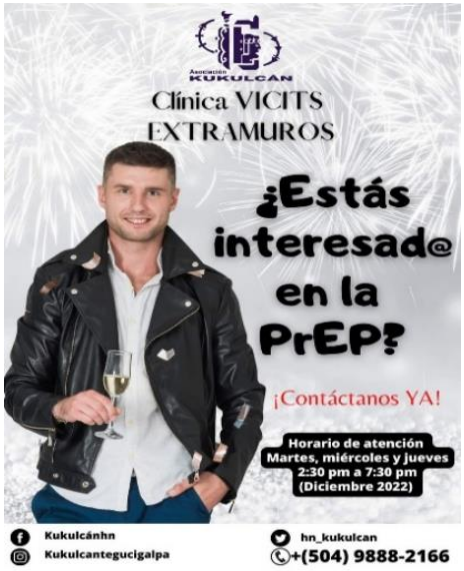

Image from Association Kukulcan Honduras
AS ONE EXAMPLE of creative outreach for PrEP

The panorama related to access to PrEP continues to be grim in Spanish-speaking Latin America, which encompasses a population of 400 million people. Only about 2 to 4% of target populations have access to PrEP in these countries.

PrEP (Pre-exposure Prophylaxis for HIV) is a medical approach, in a social context, consisting of a pill known as Truvada, which is a significant intervention related to the prevention of HIV. The pill is composed of tenofovir and emtricitibina and has a cost in the region of about $72 per year if purchased from the Pan American Health Organization's Strategic Fund. It has the same cost if purchased through Global Fund mechanisms. There is also an injectable long-acting form of PrEP, but due to intellectual property obstacles, it is unavailable in the region. **About 100,000 people were diagnosed with HIV in 2020, according to the latest UNAIDS estimates.** "Combined prevention" implies several elements including, PrEP, testing for HIV and other sexually transmitted diseases, as well as condom use, but clearly the medical intervention involving Truvada is a critical element.

Table: Number of people per country receiving PrEP in 2022 data UNAIDS based on reports

From country health systems.

Country	Population	Number of People on PrEP 2022	Number of People living with HIV
Cuba	11,000,000	316	36,000
Peru	33,000,000	646	98,000
Panama	3,000,000	989	n/a
Costa Rica	5,000,000	1110	17,000
Chile	19,500,000	1372	84,000
Argentina	46,000,000	1578	140,000
Dominican Republic	11,000,000	2411	78,000
Guatemala	16,000,000	2900	31,000
El Salvador	6,500,000	469	25,000
Paraguay	6,700,000	305	16,000
Brasil	214,000,000	48,643	960,000
Mexico	127,000,000	8,000	360,000
Ecuador	18,000,000	300	47,000

In the above table, the numbers of people on PrEP were numbers provided to PAHO/UNAIDS by country health systems as of December 2021. They are underestimates because healthcare systems fail to provide complete information, but how much is not clear. Brazil is included but is not considered part of Spanish-speaking Latin America.

The main target groups for PrEP come from so-called “Key Populations,” which include Men Who Have Sex with men, male and female sex workers, trans people, and those in serodiscordant relationships. It is not completely clear as to why heterosexual women are excluded from these populations, but all NGOs report that few, if any, heterosexual women apply to receive PrEP. Key populations are defined by the Global Fund, PAHO, PEPFAR, and other international agencies.

It is clear in Spanish-speaking Latin America that there are multiple documents, declarations, workshops, conferences, etc, related to access to PrEP that have been taking place during the past 4 or 5 years. Dozens of consultants have been involved, as well as PAHO and UNAIDS staff. The goal continues to be to “prepare” countries for PrEP implementation, although it is clear that very adequate information already exists and has

existed for years **However, what I have not seen are comprehensive documents that analyze the reason why the rollout of PrEP in the region has been so inadequate during so much time**. **There are also very few, if any, documents discussing concrete solutions to remediate the problem. So, this document is just a partial attempt to create such a document**.

PREVENTION IS DIFFERENT FROM ATTENTION

It is extremely important to recognize that there is an important difference in the nature of access to PrEP as opposed to access to attention and treatment for people living with HIV/AIDS.

HIV if untreated with antiretrovirals during a long period will in many cases, be fatal, and/or seriously affect the overall quality of life. Stigma and discrimination against people with HIV is also harmful and dangerous. For this reason, strong alliances of people living with HIV/AIDs have developed over many years in the form of ONGs, Networks, and other types of Organizaciones. Also, a very large financing structure exists in much of Latin America and the world and is very important to saving lives within populations of HIV positive people.

With PrEP, and prevention in general, the lack of access is not fatal, and the person's health does not suffer immediately, but instead only if they are exposed to and develop HIV**. So the urgency of immediate access is far less with PrEP than with access to ARV medications**. However, the delays occurring in Latin America are nonetheless unacceptable because PrEP, in the context of combined prevention including condoms, is the most important tool to reduce the incidence of new infections of HIV, which is estimated to be 100,000 per year.

The incidence of seroconversion per year is around 3% per year for people in target populations for PrEP, so again, if that were to be the case, only 30% of the target population might develop HIV over a ten-year period. On the other hand, studies and informal analysis have shown that providing access to PrEP is far more economic for health care systems than waiting until People develop HIV and have to be tested with various expensive exams, receive ARVS, and also in some cases be hospitalized. There

is an important cost/benefit ratio to providing PrEP which healthcare systems in Latin America seem to be mostly unaware of. PrEP also has a minimal incidence of secondary effects if kidney and liver tests are performed prior to beginning the intervention.

A LEXICON FOR PREP?

Without being able to comfortably put a name to a group, how do you reach out to be able to include its members in a movement for access? This is a problem in this region where some activists and leaders seem to be opposed to any separation of the HIV-positive community from the population seeking PrEP. This perceived division creates some difficulties organizing HIV negative communities. Some NGOs are composed of a combination of HIV+ people and those who are negative and would be candidates for PrEP, but most funded NGO's in the region have been historically focused on the needs of HIV-positive people. This was absolutely necessary for decades but the panorama has now changed.

(Seronegative may not be an ideal term, but it is the correct scientific term for people who do not have antibodies of a specific disease in their blood.)

It is important to develop a "lexicon" of terms that is acceptable to all populations. It is also important to minimize any struggles for control of the discourse about who is going to lead and direct the movement for access to PrEP. Unified approaches to prevention are important whenever they are possible.

There seems no doubt that all HIV+ people would be delighted if HIV were eliminated by finding a cure, and that is highly appropriate. But my perception is that there is some degree of ambivalence about PrEP in some segments of the HIV population and this is an issue that needs to be directly addressed.

Some HIV activists have openly stated that economic resources for PrEP should be postponed until all people with HIV have access to all treatments and interventions. This seems like an unrealistic argument. Prevention and treatment are related but still they are fundamentally separate issues. Those who argue against PrEP because the "scenario" for HIV treatment access is not perfect are misguided.

I think that funding sources such as PEPFAR, the Global Fund and others need to strongly address the issues of clearly defining their target populations in future funding priorities. They can also be pro-active in indicating that they are seeking to work with communities of candidates for PrEP.

Above: How the implementation of PrEP has reduced new HIV cases in four cities worldwide and even four or five years ago. (Source PAHO)

EXPECTATIONS ABOUT FOCUSING ON PREVENTION

People who are already living with a disease should not be expected to focus on preventing a disease. Just the struggles of managing the challenges of their disease can take up much of their energy. Some people with cancer or even cancer survivors do focus on prevention efforts, but the vast majority do not. I struggle with Parkinson like symptoms, but I do not focus at all on prevention so much as on possible interventions and treatments. So many older adults are dealing with health-related issues and focus on attention and treatments, not on prevention.So we should not place the expectation of focusing on HIV prevention on people who live with HIV. But at the same time we should expect them to NOT solicit financial support for an issue that they are not motivated about, and in which they do not necessarily have a trajectory of demonstrated accomplishments

and experience**. Financing agencies must prioritize those who are sincerely motivated as well as those who have the capacity to respond to an issue**. New populations need to come into the funding panorama given the dismal outcomes of access to PrEP that have occurred during past few years.

WHAT ABOUT PILOT PROJECTS?

The issue of "Pilot Projects" continues to be a theme in the region. As long as six years ago, a Senior PAHO official told me that the PAHO did not believe that Pilot Projects are not necessary anymore, and I believe that this is still the position of PAHO. The efficiency of PrEP is well established on a worldwide level and the medication used in Latin America is the same as in other parts of the world. The physicians who work in Latin American health care systems are very well informed about the use of anti-retroviral medications, and PrEP is fundamentally an anti-retroviral. Yet populations of activists continue to praise Health care systems (and in some cases NGO's) that carry out Pilot projects.

The efficiency of PrEP is 95+ % in reducing HIV infection if taken appropriately so why delay a full-scale implementation of PrEP with a pilot Project that may take two or more years? . In the cases of Ecuador and Colombia for example, pilot projects occurred even before the COVID pandemic and as such appeared to be somewhat of a pretext for those health care systems to delay access to PrEP on a larger scale. I am not questioning the quality or level of organization of Pilot Projects such as those in Ecuador, Costa Rica, Colombia and Panama. (The pilot project in Panama is financed by PEPFAR and most of the others by the Global Fund. Colombia was financed by PAHO and other sources) A fundamental issue is the lack of adequate education of the populations working for access to PrEP about issues such as its efficiency. Not infrequently, I receive complaints from HIV-positive people as to why there is no PrEP available for them**. Some activists definitely do not fully understand the concept of percentages with respect to access to PrEP and may view the numbers in the above table as "successes" when they absolutely are not successes.**

A further Issue goes beyond just the "numbers" related to PrEP. It Is an ethical Issue related to health care. It seems highly unethical to withhold an intervention that will enable

people to avoid HIV, which is a disease that currently has no cure, and requires lifetime treatment when a highly effective prevention intervention is available for $70 per year.

GOVERNMENT BUREACRACY AS A FACTOR

Clinical norms for any treatment are required before a health care system can implement it in any country. Yet in some countries the norms which apply to PrEP take many years to create and approve. **Peru is one example where PrEP cannot be implemented because clinical norms are still not approved. Once again this is a question of applying established information about PrEP to country specific nuances and it should be a process that takes only months instead of years.** So in Peru PrEP is approved for sale by some ONG's at variable prices but often as high as $70 per month. The sale of PrEP implies limiting its availability to populations who cannot afford to pay the cost charged by NGO's which includes almost all Peruvians in the target populations. In Costa Rica private pharmacies sell PrEP for $150 a month, even when PrEP is available at no cost in the public health care system.

WHAT ARE SOME SOLUTIONS FOR INCREASING ACCESS TO PREP?

SOME OF THE SOLUTIONS HAVE BEEN REFERRED TO ABOVE BUT THERE ARE MANY APPROACHES THAT CAN BE taken.

While one can look at best case scenarios from civil society, motivating governments remains a difficult issue that needs to be confronted with a variety of approaches. **For funding sources, it would seem to be valid to not only fund civil society working for increasing access to PrEP, but also NGO's focused very specifically on advocacy directed toward health care systems and top level decision makers with the goal that they include PrEP in their services.** There is an important difference as many ONG's have a discourse saying that PrEP is important, but they do not proactively manifest their activism. There seems to be a status quo that any amount of PrEP is a "great thing" even if PrEP is still only available to 2% to 4% of the key populations. The table above illustrates that the numbers of people on PrEP are extremely small wherever you look in Latin America.

ADVOCACY IS DIFFERENT FROM IMPLEMENTATION

Advocacy involves information exchange as well as overtly challenging government resistance to providing PrEP. In some cases, challenges could be legal, and in more radical contexts demonstrations, and letter writing campaigns are more appropriate. There are as many different forms of advocacy as there are activists. Funding advocacy is very different from funding implementation.

The health care system in Costa Rica recently has undergone a 3 month interruption of its access to PrEP for new users due to factors that seem difficult to analyze. Although the medication has arrived in the country as of April 28th it still has not been delivered to pharmacies in the health care system, meaning that for the moment, actual PrEP users are excluded from access. Costa Rica is supplying PrEP to up to 1,500 people in the four major target groups **but 20% of the country's population (a million people) is excluded because they cannot afford the affiliation fee for the health care system**. There is a law in Costa Rica that guarantees access to ARV treatment to people living with HIV, but there is no law guaranteeing access to PrEP, which is another of the many contradictions about PrEP. It seems to me to make little sense to only offer PrEP to 80% of the population if the goal is to eliminate HIV by 2030. The other 20% will carry the same risk of acquiring HIV as they have now.

LACK OF DATA ABOUT PEOPLE ON PREP AND PEOPLE WHO NEED IT

In order to increase access, it is also important that Health Care systems supply accurate and updated information about the number of people taking PrEP. This is a major issue because PAHO/UNAIDS collect information from countries just once a year. These Agencies recognize that the information is inaccurate and outdated. In its most recent report from 2022, UNAIDS indicated that in Spanish speaking Latin America the total of people taking PrEP in the region was about 19,000, (see table above) out of a target population of 400,000 to 600,000. This would be about 2% of the target population.

The numbers may well be higher, but it is unclear why there is a such a long delay in reporting numbers. In Ecuador for example PrEP has been available in two major hospitals for several months, but no numbers are available as to the number of people who have received access. Some activists defend this as a necessary obstacle. But obviously it is also an obstacle to reporting accurate numbers and better defining what the needs are and how to achieve them. There should be no reason why a well-functioning health care system cannot report the number of people who are taking a specific medication each month.

About two years ago, PAHO distributed a "formula" for estimating the number of people who require PrEP in a specific country (the target population) but there is no country that has reported data based on this formula.

So not only are there inaccurate figures about who has access to PrEP, but also there is a lack of data about how many people really need it. It would seem impossible to effectively implement a long term program congruent with 95/95/95 when both of the above areas of data remain undefined in terms of figures.

FOCUS ON "BEST PRACTICE" WITH REGARD TO IMPLEMENTATION

Funding sources and everyone interested in the theme need to focus on examples of "best practice" when considering how to increase access. Fundacion Kukulcan in Honduras, an LGBTI organization recently began focusing on PrEP and have a clinic devoted to the issue. According to Coordinator Dany Montecinos, in just over 4 months they have enrolled 477 people in their program. They also use creative "posters" placed in social networks and have even been so daring as to place these posters in internet applications that Men who have Sex with Men (MSM) use to find sexual contacts, including for example GRINDR.

The poster at the beginning of this article is an example of such outreach. It is very unclear about whether National Health Care systems, in their approach to outreach for MSM

would be able to utilize applications such as GRINDR due to various political and social constraints.

Another example of “best practice” has occurred in Great Britain (and many other places) where the National Health Service and NGOs have created groups **of peer educators who are trained and then asked to reach out in their networks and venues to appropriate peers and discuss PrEP**, and clear up doubts and concerns. Each peer educator is asked to recruit 20 peers for evaluation for PrEP. Pamphlets and other materials are made available. Cases of HIV in the city of London have dropped from 2600 in 2018 to 670 in 2022, a remarkable achievement attributed to PrEP. The Mayor of London proactively supported the PrEP roll out in that city. The British example could be very important in creating an increased effort to reach target populations in Latin American countries.

In Ecuador Andres Novoa has created WhatsApp chats to reach out to people interested in PrEP and other HIV related issues, and has indicated that there are nearly 1000 people involved in two different chats.

Another example of creative outreach has occurred in Guatemala (population 16 million) where Luis Gomez, Director of CAS (Collectivo Amigos contra el SIDA) reported that 2,100 people are receiving PrEP through his organization. PrEP in CAS is paid for by a grant from the Global Fund which will hopefully be extended until at least 2026. According to Gomez there have been no seroconversions (from HIV negative to HIV positive) in the population of people in the project, once again demonstrating the effectiveness of PrEP.

The promotion methodology utilized by CAS includes email outreach, websites, twitter, Instagram and Grindr and seems very successful in attracting candidates who are first tested for HIV, and syphilis. If the test result is negative for HIV, subjects are considered candidates for PrEP and are given a creatine test as a prerequisite before beginning. The Health Ministry in Guatemala still has not committed to providing PrEP so at the present time access is limited to those in CAS, and a very few other NGOs. CAS only offers PrEP in the country’s largest urban area Guatemala City.

The author of this article has organized a Spanish-language WhatsApp chat called “People United for PrEP”. (“Personas unidas para PrEP) To join, please send a WhatsApp message to +506 8390 5213.

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