

Positive Prevention by and for People Living with HIV



LIVING 2008 partnership

Discussion paper

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Contents

Executive Summary	4
Introduction	6
Positive prevention to date	9
Positive prevention by and for people who know they are HIV positive	13
1. Positive prevention is centered on the efforts of positive people	14
2. Positive prevention is not just about preventing HIV	16
3. Linking prevention and treatment.....	18
4. Ending stigma and discrimination	19
5. Positive prevention requires addressing social vulnerabilities	20
6. Everyone has a role to play	21
What should positive prevention include?.....	22
Clinical and biomedical interventions.....	22
Counseling, psychosocial and mental health care	23
Social determinants of health	24
Community and social interventions.....	24
Policy and advocacy work	25
Where do we go from here with positive prevention?	27
Involving people who know they are positive	27
New prevention technologies	28
The protective effects of antiretroviral therapy and no viral load.....	28
The risk of “reinfection”	29
Conclusion.....	31
References	32

Executive Summary

This working paper is intended to help build consensus among people who know they are living with HIV around the concept and implementation of positive prevention. The discussion does not focus on broader HIV prevention issues. However, by facilitating debates on positive prevention from the perspective of people living with HIV, the discussion seeks to inform and strengthen HIV prevention programs, policies and funding priorities.

To date, positive prevention discussions have often not included positive people, which has created two problems:

1. An overemphasis on HIV testing rather than on the needs of people who already know their status; and
2. A focus on preventing HIV transmission rather than on preventive health services for people living with HIV.

Positive prevention has steadily gained interest following the advent of antiretroviral therapy in the late 1990s, as there has been a growing population of people who know they are living with HIV and are living longer, healthier lives. Although networks, groups and individuals living with HIV have not been extensively consulted in the development of official platforms, they have long been engaged in positive prevention – in proposing and implementing programs as well as in day-to-day practices to protect and promote their own health and that of others.

A seven-month consultative process among people living with HIV worldwide and a literature review identified six critical and neglected issues around positive prevention:

1. Positive prevention is centered on the efforts of people who know they are living with HIV to learn and practice ways to promote their own health and prevent disease.
2. Although successful positive prevention will also reduce HIV transmission, positive prevention is not exclusively about preventing HIV.
3. Positive prevention is inextricably linked with access to treatment, care and support.
4. A human rights approach combating stigma and discrimination is essential to the success of positive prevention.
5. Positive prevention also requires addressing social vulnerabilities such as poverty, gender-based violence, xenophobia and homophobia.
6. Everyone has a role to play in supporting positive prevention efforts.

Better supporting the prevention needs of people living with HIV will involve a broad range of clinical and biomedical interventions, counseling, psychosocial and mental health care, social services, community and social interventions, and policy and advocacy work. It will require action on the part of health professionals, policymakers and program managers, international organizations and donors, researchers, partners and communities, and people living with HIV.

Some questions that are important to fully defining positive prevention remain unresolved. Among these are:

- How can people who know their positive status get more involved and define the political agenda for positive prevention?
- What role will new prevention technologies play in promoting the health of people living with HIV?
- To what extent does being on antiretroviral therapy protect against HIV transmission?
- What are the real risks to an HIV-positive person of being infected with another strain of the virus?

To be effective, positive prevention must involve people living with HIV in answering these questions and in all aspects of defining, developing, implementing and monitoring programs. Only this kind of fully engaged positive prevention can make a strong, new contribution to public health by effectively building upon the efforts people living with HIV are already making.

Introduction

This working paper is intended to help build consensus among networks, groups and individuals living with HIV around what positive prevention means and how positive prevention can be better addressed within broader HIV prevention policies and programs. It will review existing conceptions of positive prevention, which have tended to center on the needs of people who are HIV-negative or who are HIV-positive but not yet aware of their status, and which have mostly been developed by experts without the involvement of people who know they are living with HIV. This document will propose a different way to think about positive prevention, recommend specific services that should be included in a positive prevention package, and identify areas where further research and/or debate is needed.

The world has learned that the most effective way to combat HIV disease is a comprehensive approach linking prevention to treatment to care and support. Nevertheless, in practice these areas are still too often separated. In particular, while treatment, care and support are understood to be directed at people living with HIV and their families, prevention efforts have generally focused on people who are HIV-negative.

Some links between treatment and prevention are clear. For example, voluntary counseling and testing is an important prevention strategy, especially since some 90 percent of people living with HIV are not aware of their status. Through counseling and testing, those who test positive can get care and treatment, while those who test negative can learn to better protect themselves and receive referrals for other preventive health services, such as tuberculosis screening. Yet most people will be reluctant to seek testing unless they know that help, including treatment, will be available to them should they test positive and that their status will not lead to criminalization, stigma or discrimination.

Similarly, treatment is linked to care and support, as many people living with HIV will need to take antiretrovirals and other medicines and will also require a full range of services to maintain their health, from nutrition, to adherence support, to sexual and reproductive health care, to mental and emotional counseling.

People who have learned their status and know they are living with HIV also need prevention services. The term “positive prevention,” increasingly discussed since the late 1990s, provides a valuable opportunity to highlight the prevention needs of people who know they are positive, and a useful lens through which to understand the important linkages between prevention, treatment, and care and support. However, up to now the conversation around positive prevention has too often occurred without the involvement of people living with HIV. This has led to two significant shortcomings in most current approaches.

First, many “positive prevention” programs emphasize HIV testing, since people who know they are positive are likely to take measures to protect their own health and the health of others. Yet testing is most important to people who are not yet aware they are HIV-positive. It is irrelevant to people who have already tested and know they are positive.

Second, and related, most existing interventions focus almost entirely on preventing the onward transmission of HIV. In other words, they are centered on the prevention needs of people who are HIV-negative, not those who know they are positive. While people who know they are living with HIV welcome support in their efforts to prevent transmission, this cannot be the sole or central aim of a program ostensibly intended to provide prevention services for HIV-positive people.

If the prevention needs of positive people are to be adequately addressed, people who know they are living with HIV must be involved in defining and developing interventions. The failure to acknowledge this means that a valuable opportunity to enhance public health by creating positive prevention programs that truly serve positive people is being missed. Worse, existing approaches to positive prevention risk actually increasing the burdens on the lives of people living with HIV, by reinforcing stigmatizing messages and fueling discriminatory attitudes towards people who are HIV-positive. Most counter-productively, such discrimination falls hardest on the small proportion of people living with HIV who have, as public health campaigns advise, gone for testing and revealed their status to others.

From January – August 2008, people living with HIV around the world have worked to define and own positive prevention. An on-line forum was facilitated involving 70 members. Working Group members coordinated national and regional face-to-face group consultations with people living with HIV in collaboration with the Caribbean Regional Network of People Living with HIV/AIDS (CRN+), European AIDS Treatment Group (EATG), GNP+ North America, the International Community of Women Living with HIV/AIDS (ICW), the Network of African People Living with HIV/AIDS (NAP+), and the Red Cross/Red Crescent Network of People Living with HIV (RCRC+). Participants from Africa, the Caribbean, Europe, Latin America, the Middle East and North America shared programmatic and research documents, stories and experiences; discussed and debated why positive prevention matters; and identified their positive prevention needs. In addition, a literature review was conducted to improve understanding of how positive prevention has – and has not – been defined to date.

People living with HIV welcome the long-overdue attention to their preventive health needs. They acknowledge and willingly accept their responsibility to protect and promote their own health, and know that by doing so they can help others. Their partners have a role to play as well, as do governments, health professionals, researchers, donors and non-governmental organizations. A culture of shared responsibility—that encourages every individual to take personal responsibility for his or her own health while also encouraging communication, equality and mutual support in relationships, all in the context of supportive policies and programs—is the only way to sustain prevention for people who are HIV-positive *and* for people who are HIV-negative.

Today positive prevention for me entails managing the complex dynamics of living in a discordant couple in the era of effective treatment and undetectable viral load. In reality this means no more condoms when I have sex with my partner – a mutual and informed choice we have both made. It means treatment adherence – something which as an ex drug user I am very good at. It means aiming to visit the gym at least three times a week, whether I make it or not. It means taking the time to cook and eat well in spite of a crazy schedule that spans multiple time zones. It means annual pap smears, monitoring my CD4 and viral load and keeping track of my hepatitis C infection - now my major health concern.

I am privileged to have access to all the prevention commodities and services I need in order to ensure my well-being, but sadly this is not the case for many people living with HIV who do not have access to condoms, ART, sterile injecting equipment, post exposure prophylaxis, PMTCT, clean water, good nutrition, housing, employment or information on prevention.

For me, positive prevention is also about those of us living with HIV defining our own prevention needs as they relate to our lives and the lives of those close to us. It is about us setting an agenda that has until now mostly been set by others for us – or in some cases against us. It is about kicking back against increasing efforts to criminalize those of us knowingly living with HIV, efforts that portray us as agents of infection, who are expected to assume total responsibility for all infections that occur.

Scarlet Juanita Hassan

Positive prevention to date

People living with HIV have always been at the forefront of efforts to broaden HIV prevention programs to include both HIV-positive and HIV-negative people.ⁱ At its heart, positive prevention means integrating prevention, treatment, care and support. Improving the health and lives of people living with HIV through care and treatment in turn reduces the risk of infectious diseases. This idea was first publicly proposed in 1989,ⁱⁱ but did not receive extensive attention or support until the late 1990s. By then, the availability of combination antiretroviral therapies meant that more people were living longer, healthier lives with HIV. This drew new concern to prevention among positives for several reasons.

For one, in places where treatment is available, people might be more willing to seek testing.ⁱⁱⁱ Simultaneously, treatment meant that HIV-positive people were living much longer. These two developments, in combination, meant that there were suddenly larger numbers of people who were still alive and knew they were living with HIV, and who sought care, support, and treatment services. Also, because people living with HIV began to visit health care facilities to obtain treatment, there were more frequent and ongoing opportunities to offer preventive services.

Second, being on treatment helped many people living with HIV to regain strength and energy, which could increase the likelihood that some people would engage in risky behavior. Further, some evidence suggested that in certain communities the availability of treatment could lead people – HIV-positive and HIV-negative – to discount the seriousness of the risk of HIV disease, and so relax their efforts to reduce their risks.^{iv} Research also showed, however, that most people who learn they are HIV-positive reduce risky behavior.^v Many experts thus stressed the importance of maintaining prevention efforts even while scaling up treatment, and some proposed the need for specific prevention strategies tailored for people who know they are living with HIV.

It was also thought that the availability of treatment would reduce the stigma associated with HIV. In an atmosphere of stigma, discrimination, gender imbalances, and relationship violence, even the most basic elements of positive prevention – knowing your status, communicating with your partner, seeking care and support services – can be impossible for positive people to practice. With the assumption that people with access to treatment would be better able to disclose and seek services related to their status, it became important to identify more precisely what prevention services were needed.

Finally, with an HIV diagnosis no longer viewed as the end of a person's life, efforts to improve the quality of life with HIV gained ground. More attention was paid to relationships and intimacy, which inevitably brought up questions of disclosure and safer sex for discordant couples. In addition, people living longer, fuller lives with HIV were more likely to have a wide range of preventive health needs, including sexual and reproductive health care.

Components of positive prevention have been practiced in many countries since the 1980s, although not initially labeled as such. For example, the Chilean network of people living with HIV, Vivo Positivo, launched a prevention program in 2001 designed to enhance the health and quality of life of people

living with HIV.^{vi} Specifically named “positive prevention” projects were underway across the United States and Canada by the beginning of the 2000s.^{vii}

In France, the Agence Nationale de Recherches sur le Sida et les Hépatites Virales (ANRS) organized a meeting in 1998 to explore existing evidence around prevention among people living with HIV, focusing on the social and relationship factors that can complicate condom use and disclosure of positive status to partners and others.^{viii} In 2001, the U.S. Centers for Disease Control and Prevention (CDC) launched the Serostatus Approach to Fighting the HIV Epidemic (SAFE) program.^{ix} SAFE focused a significant portion of its efforts on HIV-positive people who do not know their status, setting its first goal as to scale up testing. SAFE also included efforts to increase access to and use of health care services, including antiretroviral therapy, among people who know they are living with HIV, and to reduce risky behavior among those who know and those who do not know their status.

In 2003, the CDC incorporated prevention for positives into a broader new initiative, Advancing HIV Prevention (AHP).^x Like SAFE, while AHP addresses some health care needs of people living with HIV – such as STI screening, substance abuse treatment, and prevention of opportunistic infections – the clearly stated program goal is to reduce the number of new HIV infections, and to do so by changing the behavior of people living with HIV.

The U.S.-based National Association of People living with AIDS (NAPWA) immediately criticized the AHP program, arguing that it would increase stigma and blame directed at people living with HIV, while including no plan for care and treatment for the thousands of newly diagnosed people living with HIV likely to result from the program’s emphasis on testing. NAPWA described the development of AHP as “secretive” and “politically inspired,” and pointed out that without the involvement and support of people living with HIV, positive prevention is unlikely to be effective.^{xi}

At about the same time, the International HIV/AIDS Alliance (the Alliance) shared a draft background paper that took a broader and more nuanced approach to positive prevention.^{xii} The paper attempted to outline an ethical framework for positive prevention. The first two categories of this framework focused on ways to promote testing, improve access to treatment, and provide counseling around safer behavior for people who know, as well as those who do not yet know, they are living with HIV. The second two categories addressed the need for environmental changes. They proposed, for example, facilitating peer support groups, involving people living with HIV in program design and policy decisions, and generally working to develop a more supportive legal and policy environment.

The Alliance solicited feedback on this draft document and eventually published it as a more formal guide for NGOs and service providers in 2007.^{xiii} The draft also influenced others’ thinking about positive prevention. For example, in 2004, the Global HIV Prevention Working Group published *HIV Prevention in the Era of Expanded Treatment Access*,^{xiv} which called for increased attention to positive prevention as one key part of a broader prevention agenda. Specifically, it promoted:

- Tailored prevention programs (including counseling to help with disclosure, practical information about the risk of HIV transmission when on antiretroviral therapy, and promotion of safer behavior);
- Financial support to and involvement of organizations of people living with HIV; and
- Community-based efforts to combat HIV-related stigma, which should increase use of testing, treatment and prevention services.

Like the Alliance paper, the HIV Prevention Working Group report called attention to the need for change in the broader environment, including greater support to networks of people living with HIV and the critical importance of overcoming stigma. It also focused largely on people who know their status. However, as people living with HIV pointed out,^{xv} both reports defined “prevention” almost exclusively as the prevention of onward HIV transmission. The broader preventive health care needs of people living with HIV – and the many ways that addressing these needs could enhance well-being and reduce disease – were ignored.

In 2005 UNAIDS proposed an approach better centered on the lives of people who know they are living with HIV. Here, positive prevention was described as having three important facets:

The aim of prevention for people living with HIV is to empower them to avoid acquiring new sexually transmitted infections, delay HIV disease progression and avoid passing their infection to others.^{xvi}

UNAIDS also explicitly acknowledged the critical efforts of people living with HIV to demand, promote and practice prevention. It did not include HIV testing as a positive prevention intervention, as those who already know their status do not need a test. Instead, its specific prevention guidelines for people living with HIV recommend:

- Ensuring legal protection and social support for people living with HIV;
- Ensuring post-test counseling;
- Providing support for groups and networks of people living with HIV; and
- Supporting initiatives to encourage the greater involvement of people living with HIV.^{xvii}

Instead of promoting behavior change, these guidelines focused on providing services and support for people living with HIV. More than any previous approach, they positioned positive prevention as a set of interventions for the benefit of people living with HIV and focused on those who had the courage to learn their status.

In a set of draft guidelines published in 2007, the World Health Organization described positive prevention as having three components: healthy living, healthy sexual activity, and the involvement of

people living with HIV.^{xviii} The guidelines compiled technical evidence and an extensive list of recommendations for preventing illness and promoting health among people living with HIV and for preventing HIV transmission. They included a wide range of medical interventions, psychosocial support and counseling, and household-level interventions such as the provision of safe water.

Groups of people living with HIV have proposed a still broader package of activities and interventions. In 2004, NAPWA outlined a comprehensive range of prevention needs, including medical care, housing, substance abuse treatment, education and economic opportunities, mental health services, self-esteem support, and domestic violence prevention and services.^{xix} They also stressed the need to address questions of sexuality and intimacy, as well as the importance of conceptualizing positive prevention as a shared responsibility. They wrote:

People living with HIV are willing to accept a special responsibility for avoiding transmission, but we need prevention programmes to communicate a message of responsibility to our partners as well.

In early 2008, the Ontario Gay Men's HIV Prevention Strategy approved a positive prevention platform that similarly emphasized shared responsibility.^{xx} This platform also placed top priority on improving the quality of life of people living with HIV, although it did not go as far as the NAPWA document in defining the types of services this might encompass. In India, the Asia Pacific Council of AIDS Service Organizations has been working since 2005 on the Prevention and Treatment Advocacy Project, which integrates work around care and prevention within a human rights framework. In Chile, Vivo Positivo's prevention activities include relationship counseling, psychological services, and nutritional assistance, as well as broad preventive medical care.

Positive prevention by and for people who know they are HIV positive

Positive prevention is about preventing illness and promoting good health among people who know they are HIV-positive. This includes preventing new infections (such as hepatitis, gonorrhea, or infection with a different strain of HIV), reducing drug-related harm, promoting healthy living, and enhancing the quality of life generally. Positive prevention is effective only when positive people take action to care for themselves. But everyone has a role to play in making positive prevention work. People who know they are living with HIV need support and acceptance to be open about their status, so they can actively seek health services and talk about prevention with others. They need protection from violence and the threat of violence. They need social services to ensure they do not need to resort to unsafe practices for survival. And they need to be able to use health care services to keep them strong. Positive prevention means promoting healthy living and empowering people living with HIV to continue to take responsibility for their own health and lives.

At the HIV + Monaco Conference in January 2008, people living with HIV formed a working group to investigate issues of positive prevention. The group acknowledged that most people who know their HIV-positive status are not interested or engaged in positive prevention as it has been previously defined. They decided to find out specifically what other people living with HIV think about positive prevention, in order to expand on the work done to date and build a holistic definition of the concept. In a position statement, this group emphasized the need for people who know their status to get involved in positive prevention. To ensure that the focus is placed on the prevention and health needs of people who know they are living with HIV, positive prevention must be defined and owned by positive people.

10 razones por las que necesitamos hacer prevención positiva

1. Para promocionar y promover la salud integral
2. Para mejorar la calidad de vida
3. Involucramiento en el diseño, elaboración, aplicación y evaluación de las personas con VIH en políticas públicas
4. Protección de la propia salud por el estado y otros actores
5. Participación en las tomas de decisión porque promueve la participación de las personas con VIH
6. La prevención positiva es igual a la calidad de vida a través de la atención médica, psicológica y sexual
7. Es una actividad que puede mejorar la perspectiva social, económica y espiritual.
8. Dar un enfoque multidisciplinario en general
9. Quitar el estigma de la palabra positivo a la prevención. Hacerla verdaderamente positiva
10. Ofrecer las herramientas de prevención para que las personas elijan
11. Alcanzar las metas de acceso universal para reducir el impacto en los ámbitos de los derechos humanos, salud y económico
12. Rescatar experiencias y vivencias de las personas con VIH para hacer más efectivas las estrategias

Consultation organized by La Red Mexicana de Personas que Viven con VIH/SIDA, June 2008

Positive prevention encompasses emotional, physical and psychological health. This means that it must address a range of issues that are largely ignored by existing interventions, such as nutrition and exercise; sexuality, intimacy and relationships; physical and sexual abuse; and harm reduction, needle-exchange and drug substitution therapy. Attention to these needs will help people living with HIV to maintain and promote their health.

By protecting themselves, people living with HIV also diminish the likelihood of passing on any infections, including HIV, to others. However, the positive prevention working group stressed that preventing transmission is a shared responsibility. Indeed the vast majority of new infections are transmitted among the 90 percent of people with HIV worldwide who are not aware of their status. Without in any way diminishing the importance of HIV prevention efforts, the group insisted that positive prevention must promote health and prevent immune suppression for those who know their positive status.

The working group organized a global series of consultations to share ideas, opinions and experiences around positive prevention. Through this comprehensive process, six critical elements emerged:

1. Positive prevention is centered on the efforts of people who know they are living with HIV to learn and practice ways to promote their own health and prevent disease.
2. Although successful positive prevention will also reduce HIV transmission, positive prevention is not exclusively about preventing HIV.
3. Positive prevention is inextricably linked with access to treatment, care, and support.
4. A human rights approach combating stigma and discrimination is essential to the success of positive prevention.
5. Positive prevention also requires addressing social vulnerabilities such as poverty, gender-based violence, xenophobia, and homophobia.
6. Everyone has a role to play in supporting positive prevention efforts.

1. Positive prevention is centered on the efforts of positive people

To be meaningful to and practiced by people living with HIV, positive prevention must, ultimately, improve their quality of life. In consultative workshops, people living with HIV explained that their ideas of positive prevention encompass a wide array of preventive health needs. For example, they identified exercise,^{xxi} nutrition,^{xxii} drug counseling,^{xxiii} psychosocial and mental health care,^{xxiv} and spiritual care^{xxv} as key elements of a healthy lifestyle. Positive prevention means living longer, yes, but it also means living

better.^{xxvi} It means being able to have a satisfying sex life.^{xxvii} It means sharing one's life with a companion.^{xxviii} It means being able to have a family.^{xxix} It means living with freedom and dignity.^{xxx}

Learning that one is HIV-positive is a first step in positive prevention. In Kenya, participants explained, "Positive prevention begins when you take a positive step to go for VCT and when one knows one's status, prevent infection and live positively." The next steps involve learning how to live safely and healthily. People living with HIV have a range of medical needs, from tuberculosis screening to maternal health services to oral and dental care. They need education on why, where and how to meet these needs – and the relevant services need to be available and accessible.

Definitions of Positive Prevention

1. It is a way of avoiding infection and re-infection.
2. It is prevention and interventions initiated by PLHIV but involve all sexually active people.
3. It is doing something to stop something happening.
4. Preventing something and avoiding negative effect
5. Positive prevention is prevention initiated by PLHIV.
6. Positive prevention is knowing your status.
7. It is preventing people not getting the virus and those with infection from being re-infected.
8. It is prevention by those who know their status to prevent infecting others and being re-infected. Positive prevention begins when you take a positive step to go for VCT and when one knows one's status, prevent infection and live positively.
9. Positive prevention is the way I take myself so that I do not get into more problems e.g being infected or infecting others. I declare my status and share how I have lived positively.
10. It is greater involvement of PLHIV.
11. Let us admit that concepts emerge every day-let's admit we do not know about positive prevention.

Consultation of positive teachers (KENEPOTE) and religious leaders infected and affected by HIV and AIDS (KENERELA+) in Kenya

Positive prevention also means enhancing well-being more generally. In Morocco, participants explained that positive prevention is "to improve our physical and psychological lives."¹ In Bahrain, it was "to ensure a prosperous and secure life for people living with HIV."² In Mexico, "Positive prevention is equal to quality of life in terms of medical, psychological and sexual attention."³ Because many people living with HIV are poor or low-income (because people who are low-income are socially vulnerable and at increased risk of HIV infection, and because stigma and marginalization around being HIV-positive can

¹ « Pour améliorer notre vie psychique et psychologique. »

² « Assurer une vie prospère et sécurisée pour les personnes vivant con VIH »

³ "La prevención positiva es igual a la calidad de vida a través de la atención médica, psicológica y sexual"

make it difficult for people to support themselves), proper food, housing, education and employment opportunities can be essential to positive prevention. Malnutrition is a particular problem in low-income countries and can specifically exacerbate disease progression among people living with HIV.^{xxxii}

Even where sufficient food is available, people living with HIV need to learn how to take care of themselves by eating properly and getting enough exercise. They may need to try to quit smoking or stop using drugs. Workshop participants spoke in terms of their own responsibility to learn, find solutions, and care for themselves. To participants in Yemen, positive prevention meant “to come out from the disease and to inform ourselves and [have] strength [and] confidence in ourselves.” Kenyan participants explained, “Positive prevention is the way I take myself so that I do not get into more problems e.g. being infected or infecting others. I declare my status and share how I have lived positively.”

The responsibility of people who know they are living with HIV to practice positive prevention goes hand-in-hand with the need for these same people to take the lead in developing positive prevention programs. Consultation participants around the world stressed the importance of involvement. For example, Toronto participants said, “What is positive is that people living with HIV must be involved in the development of positive prevention programs.” To a large extent, the weaknesses of current approaches could have been avoided if positive people had been involved from the beginning, as NAPWA and others have pointed out.

People living with HIV in Mexico underscored that they and their peers have been practicing positive prevention all along, even while unacknowledged:

The prevention session allowed us to put forward a common concept of prevention from the public health perspective, and to recognize that all the participants were implementing positive prevention actions and strategies though we did not clearly understand them to be positive prevention.⁴

2. Positive prevention is not just about preventing HIV

Because it is centered on the lives of people who know that they are already living with HIV, positive prevention cannot, by definition, be strictly about preventing HIV infection. Programs designed to protect HIV-negative people from being infected by their HIV-positive partners are not positive prevention – they are simply prevention programs.

⁴ La sesión de prevención permitió poner en común el concepto de prevención desde el enfoque de la salud pública, reconocer que todas las y los participantes estamos implementando acciones y estrategias de prevención positiva las cuales no se tenía claro que eran de prevención positiva.

People who know they are living with HIV are certainly not unconcerned about HIV transmission. In every consultation, participants stressed the importance of not transmitting the virus. For example, in Lebanon, participants said they need positive prevention services so they do not “unintentionally hurt someone.”⁵ Canadian participants “don’t want to pass on our virus to others,” because “people with HIV care about their partners, children and the community.”

Indeed, HIV-positive people have always gone to great lengths to protect their partners from infection. People living with HIV also support and welcome many of the elements included in existing “positive prevention” programs. For example, nearly universally, workshops identified voluntary counseling and testing as a critical need. They stressed the importance of disclosing status to partners, and they emphasized the need to use condoms. In making these points, though, they insisted that while people living with HIV are willing to – and already do – take personal responsibility for these actions, this responsibility is not enough. Testing needs to be available, affordable, and non-stigmatized. Sexual partners – seropositive or seronegative – need to be willing to talk about and practice safer behaviors. And sufficient supplies of male and female condoms and lubricants must be available.

Even further, people living with HIV claim responsibility for educating others on how to protect themselves. In Southern Sudan, a participant explained, “Positive prevention to me means not to transmit the disease to others and advocate for more awareness to those who are not affected.” In Tunisia, “Positive prevention to [people living with HIV] means speak out against HIV/AIDS and greater awareness to the others.” In the United States, “A lot of us are capable” of educating others about prevention. Indeed, people living with HIV have long taken the lead in speaking out to create greater awareness of HIV and the importance of prevention.^{xxxii}

People who know they are living with HIV have always worked to prevent the spread of HIV. And positive prevention will enhance these efforts: when positive people are able to stay healthy and protect themselves from infections, they will also be less likely to transmit infections to others. But ultimately, positive prevention is about people living with HIV taking responsibility for their own health and well-being – not about making people living with HIV responsible for the health of others.

People living with HIV in Canada expressed a broad, comprehensive sense of positive prevention:

“It should be a part of PLHIV health promotion and staying well. The emphasis on reducing transmission to others should be a key part but rooted in the health and well-being for PLHIV. It is closely tied to the sexual and reproductive health rights of PLHIV and that sexual expression does not end in becoming HIV positive.”

⁵ “faire du mal non intentionné à quelqu’un. »

3. Linking prevention and treatment

Most discussions of positive prevention recognize that prevention and treatment are closely linked. The effects of treatment on the lives and health of people living with HIV was an early driver of attention to the need for positive prevention. In addition, treatment services provide an important entry point to the delivery of positive prevention services.

Treatment is also itself an important facet of positive prevention. Treatment lowers viral load, and people with a lower viral load are less likely to transmit the virus.^{xxxiii} Beyond this, however, to people living with HIV, being on treatment is central to health and well-being. It is, in fact, the core of preventive health care for positives.

Discussions among different groups of people living with HIV addressed three distinct aspects of treatment as positive prevention. First is the fundamental right to treatment. In Algeria, for example, positive prevention was described as “to have the right to get treatment without interruption.”

Second is the practical, on-the-ground reality of treatment access. Participants in Algeria also said part of positive prevention is “to avoid the out of stock of treatment” and stressed the right to have treatment “without interruption.” In Yemen and Tunisia, participants addressed the need to *continue* treatment over the long term. In Tunisia, concerns were also raised about access to newer, more expensive drugs. In Lebanon, participants said that part of positive prevention is “to maintain a job and income so I can obtain treatment.”⁶

Finally, participants stressed the responsibility of people living with HIV to practice positive prevention by adhering to treatment regimens. In Jamaica, one group described positive prevention as “taking your medication on time all the time.” In Lebanon, participants said it is “to take the medications the right way.”

Since these three elements are clearly linked – a person cannot adhere properly to a treatment regimen if drugs are unavailable or become prohibitively expensive – these statements underscore the need for a comprehensive approach linking testing and counseling, drug access, treatment literacy, and ongoing care and support. They also highlight the need to address treatment – like prevention – as a shared responsibility. People living with HIV understand that adhering to treatment regimens, while difficult, is a necessary part of keeping themselves healthy. In turn, communities, health care providers, governments, international organizations, donors, and drug manufacturers must commit to ensuring that the most appropriate drugs are available and that people living with HIV have the information and support they need to use treatment properly. Only then can the health of people living with HIV be protected and promoted.

⁶ “avoir toujours un travail et une rentrée financière afin d’assurer mon suivi.”

Despite impressive international efforts to scale up access to treatment, the vast majority of people around the world who need antiretroviral therapy are not receiving it. According to the World Health Organization, by the end of 2007, fewer than a third of people who needed HIV treatment had access.^{xxxiv} Continued efforts to reach more people with treatment are essential to the success of any positive prevention program.

“We have been having some changes and interruptions in our treatment regimes because many times when we go for ARVs clinic we are being asked for some money so we tend to miss the dose even for a week or month till we get some money to pay for that service. Another problem is lack of enough food, especially to us women who are under treatment. The consequences were: not finishing my dose which caused infections, staying without a dose till the clinic day and lie to the service provider that I have finished my dose, fighting with my husband or even chasing me out of the house when I refuse giving him my dose.”

Member of the International Community of Women Living with HIV, Tanzania

4. Ending stigma and discrimination

The links between stigma and positive prevention have been described in earlier analyses and recognized in positive prevention programs.^{xxxv} Stigma and fear of discrimination can inhibit people from learning their HIV status – and individuals cannot practice positive prevention if they do not know they are positive. Stigma and fear of rejection can also prevent people who know they are living with HIV from disclosing their status to partners, families or health care providers.^{xxxvi} This can make it difficult to practice safer sex, and it means that people living with HIV lack access to the specialized health care services – including but not limited to treatment – that they need.

To people living with HIV, however, ending stigma and discrimination is not only an instrumental tool to enhance positive prevention. It is itself an essential element of positive prevention. Indeed, the effect of stigma on self-esteem and life prospects is one of the most important limitations on the quality of life of people living with HIV. As participants in Mexico explained, one reason to practice positive prevention is “To end the stigma of the word ‘positive’ in prevention: to make it truly positive.”⁷ Canadian participants said, “We don’t want to be judged or discriminated against for being HIV-positive.”

Many stressed the ways that stigma and discrimination prevent them from living complete, fulfilling lives. In Yemen, one identified goal of positive prevention is “to integrate people living with HIV in the

⁷ “Quitar el estigma de la palabra positivo a la prevención. Hacerla verdaderamente positiva.”

society.” In Morocco, positive prevention is important “so that I can integrate myself effectively into society.”⁸

HIV-related stigma has internal as well as external manifestations. In Lebanon, participants talked about the need to “maintain self-esteem.”⁹ Kenyan participants said that positive prevention “reduces stigma and discrimination with oneself and also in the community.” The Positive Prevention Working Group stated that positive prevention must address stigma and prejudice within as well as beyond people living with HIV.^{xxxvii}

Reducing stigma and discrimination thus requires both individual and group counseling as well as broad social interventions. Participants in Tunisia spoke specifically about the role of the media in reinforcing stigma, and included media education and sensitization as part of positive prevention.

Participants in Yemen captured the need for action in reducing stigma and discrimination, defining positive prevention as “to change positively the thoughts of society towards people living with HIV, and to perform it.”

5. Positive prevention requires addressing social vulnerabilities

Social factors including poverty, homelessness, sexism, racism, homophobia, xenophobia, violence and abuse shape the lives of many people with HIV. Workshop participants in Mexico explained that “Positive prevention recognizes that HIV is fortified by inequality, disparities based on gender and sexuality, a lack of knowledge, and poverty.”¹⁰ In Antigua, participants listed discrimination, poverty, imprisonment and low literacy among the major barriers to effective positive prevention. People living with HIV cannot always change their individual behaviors until these kinds of human rights abuses – which often made them vulnerable to HIV infection in the first place and continue to impede their ability to care for themselves – are addressed.

Gender inequalities and fear of violence can be major obstacles to the ability of many people living with HIV to practice positive prevention. Women often lack the power to insist on condom use, to go freely to health clinics for care and treatment, to obtain adequate nutrition, or to work and control their own income. Under these conditions, it is very difficult for women living with HIV to protect their health.

⁸ “Pour savoir m’intégrer dans la société d’une façon efficace. »

⁹ “garder une estime de soi.”

¹⁰ “La prevención positiva reconoce que el VIH es fortalecido por la inequidad y a las desigualdades de género, la sexualidad, la falta de conocimientos, el rol de la sociedad y la pobreza.”

Members of immigrant and minority groups also face special barriers. Participants in Washington, DC pointed out that in addition to a general environment of discrimination, immigrants may have specific problems with health care providers who do not understand their cultural background and health care needs. The problems are magnified for people who belong to more than one vulnerable group. For example, participants in Toronto described the extreme discrimination faced by Native women living with HIV, who are driven from their homes and not allowed to be buried on the reserve.

While positive prevention programs cannot be expected to end these kinds of major social problems and human rights abuses, they should acknowledge the many obstacles people living with HIV face, provide assistance and counseling, and work at the national and community level to fight discrimination and inequality. Mexican consultation participants stressed the importance of advocacy work, saying that it should be “linked with the promotion, negotiation and defense of human rights, with the ultimate objective of creating a favorable environment for prevention.”¹¹

6. Everyone has a role to play

As discussed above, positive prevention is by and for people who know they are living with HIV. Nevertheless, it is important to recognize that, like everyone, people living with HIV are embedded in a web of personal relationships that can have both positive and negative health effects.^{xxxviii} People living with HIV in Barbados stressed that “Positive prevention requires education of partners.”^{xxxix} In Trinidad, participants specifically cited partners’ unwillingness to use condoms as a barrier to positive prevention. These experiences are echoed in published research, which has shown that partners often become angry when positive women or men ask to use condoms or disclose their status.^{xl} Depending on their circumstances, people living with HIV may risk rejection, violence, loss of income (for example, for sex workers) or even death, upon disclosing their status or suggesting condom use.

Conversations and communications between couples should not be limited to negotiating the use of condoms, of course. Strong relationships – within partnerships, families and communities – are an important part of emotional health. Positive prevention must address relationship dynamics overall, both because relationships are important in and of themselves and because of the way these relationships can affect the ability of people living with HIV to practice positive prevention.

Beyond the community level, too, others can play important roles in making positive prevention work. As the next section will describe, health professionals, policymakers, program managers, international organizations, donors, and researchers must all take action for positive prevention to be successful.

¹¹ El trabajo de incidencia política se refiere a las actividades vinculadas con la promoción, gestión y defensa de los derechos humanos cuyo objetivo último es crear ambientes favorables para la prevención.

What should positive prevention include?

All kinds of people, around the world, know they are living with HIV, and no generic package of services will meet everyone's preventive health care needs. Children's, young people's, and women's needs are different from those of men. People living in resource-limited or tropical countries may need services such as clean drinking water or insecticide-treated bed nets.^{xii} Sex workers, injecting drug users, men who have sex with men, transgenders, and prisoners who reveal their positive status can face extreme stigma and discrimination, from their HIV-negative peers among others, and have unique health needs. Positive refugees, migrants, and mobile populations often also face stigma and discrimination and are often not able to access services because they are not citizens or legal residents. Positive indigenous people can also find it hard to obtain proper care.

In addition to preventive medical care, improving the quality of life of people living with HIV requires stronger psychosocial supports. People living with HIV are often among the most vulnerable and marginalized individuals in their societies. The same factors that make people vulnerable to HIV infection – poverty, gender inequality, racism, homophobia, xenophobia – can also make it hard to live a healthy, satisfying life after an HIV diagnosis. Positive prevention must work to break down these barriers, and help people living with HIV overcome them.

Further, positive prevention needs to be linked to efforts to reduce stigma and discrimination, which involves working with partners, families, communities, and the public at large.

Finally, no single intervention on its own can be effective. It is not enough to only provide condoms, or provide nutritional assistance, or support peer counseling groups, for example. A comprehensive package of positive prevention services should encompass clinical and biomedical interventions, psychosocial and mental health care, social services, community interventions, and policy and advocacy work. Some of the elements that could be included in such a package are described below.

Clinical and biomedical interventions

- Voluntary HIV testing and counseling that is confidential, consenting and with appropriate pre- and post-test counseling.
- Diagnostic testing to monitor HIV and the immune system.
- Antiretroviral therapy, including beyond first-line drugs, information and counseling on treatment (treatment literacy), and services to support adherence to drug regimens.
- Regular screening, diagnosis and treatment of tuberculosis.

- Regular screening, diagnosis and treatment of sexually transmitted infections and hepatitis B and C.
- Prevention of opportunistic infections through drug prophylaxis and environmental interventions (nutrition, clean water, bed nets), and treatment when infections occur.
- Ensuring adequate, affordable supplies of male and female condoms and lubricants, and promoting their use.
- Sexual and reproductive health care (contraceptive services, maternal health services, and gynecologic and urologic care).
- Harm reduction services for HIV-positive drug users, including needle exchange and drug substitution programs that take into account special needs, including drug interactions with antiretrovirals.
- Programs to support positive pregnant women and antenatal care to help them promote the health of their unborn child, including preventing parent-to-child transmission.
- Home-based care to bring services directly to people who cannot reach health care facilities for counseling or care.
- Oral and dental care to help prevent infection (since HIV symptoms are often first seen in the mouth).
- Nutritional education, counseling and assistance.

Counseling, psychosocial and mental health care

- Diagnosis, counseling and treatment for depression and other mental health issues, which are common among people living with HIV.
- Counseling to build self-esteem.
- Relationship counseling.
- Risk-reduction counseling, including both individual counseling and skills-building workshops on dating, disclosure, and communication with partners. Such workshops should take place in safe environments where people living with HIV can speak openly and increase solidarity.
- Counseling for sero-discordant couples. These sessions should acknowledge the need for couples to express intimacy through sex and work to identify ways to have sex more safely.

- Counseling around exercise and “buddy systems” to encourage regular physical activity.
- Domestic violence prevention and services.
- Peer support groups, especially for vulnerable groups including women, young people, young people born positive, sex workers, injecting drug users, and men who have sex with men.
- Substance use interventions sensitive to the needs of people living with HIV.

Social determinants of health

- Help in obtaining a safe, affordable place to live.
- Services to ensure transportation to health clinics and places of employment.
- Child care services to enable parents to obtain health care, to work, and to participate fully in counseling and support activities.
- Support to stay in school and obtain job training.
- Employment assistance and income-generating and microcredit programs.
- Legal assistance to cope with issues such as HIV-related discrimination, insurance coverage, child custody or parole.

Community and social interventions

- Advocacy and counseling trainings to support the greater involvement of people living with HIV.
- Specific training for health care providers in the health care needs of people living with HIV, as well as counseling and training on treating people living with HIV with dignity and respect. People living with HIV must be involved in both the design and the delivery of these training modules.
- Mass media campaigns to combat stigma and discrimination against people living with HIV.
- Training for journalists in how to report accurately and sensitively on issues related to people living with HIV.

Policy and advocacy work

- Advocates and NGOs should press for the greater involvement and representation of people living with HIV on HIV-related boards and committees, including but not limited to efforts focused on positive prevention.
- Efforts to expand toward universal access to antiretroviral therapy should continue.
- Antidiscrimination laws should include specific provisions barring discrimination on the basis of HIV status.
- Transmission of HIV should not be criminalized.
- Sex work, same-sex relationships, and particular sexual practices – such as anal sex – should be decriminalized, to enable people living with HIV from marginalized groups to safely obtain health services and communicate honestly with health providers.
- Health systems should be pressured to ensure adequate supplies and access to health commodities, particularly those related to stigmatized activities (condoms, lubricants, clean needles) and, where needed, education efforts should be undertaken to counter misleading attempts to disparage condom effectiveness.
- Efforts to develop new HIV prevention technologies, in particular female-controlled ones, should address the needs of people living with HIV and should involve people living with HIV in research trials and oversight.

It is critically important that people who know they are living with HIV be actively involved in the design, implementation, and monitoring of all of these activities. The involvement of people living with HIV is not just another bullet point on a list of interventions. Positive prevention cannot succeed without the engagement, input, and active support of positive people. Positive people are the experts when it comes to identifying the needs of people living with HIV, and they are also best positioned to deliver effective support services to their peers.

Another important element in defining a positive prevention program is identifying the indicators by which success will be measured. Reducing the number of new HIV infections is a critical indicator in any prevention program, yet this is not the focus of positive prevention defined by and centered on positive people. Positive prevention programs must address improvements in the survival and in the quality of life of people living with HIV. For example, this might be measured by the number of known positive people who

- receive treatment for depression, nutritional support, family planning counseling and information, substitution therapy for drug dependence, regular and quality dental care, tuberculosis diagnosis and treatment, or bed nets;

- can be effectively treated with first-line drugs (and the length of time before they need to change regimens);
- participate in peer counseling sessions;
- reduce their alcohol and drug intake;
- receive employment training and scholarships to attend higher education;
- participate in income generating activities and find employment;
- are able to send their children to school; or
- are able to put shoes on their own and their children's feet.

Qualitative indicators, such as decreasing levels of discrimination experienced by positive people and increasing confidence in negotiating safe relationships, are also important to track. Overall, more work should be done to identify the indicators most meaningful to people who know they are living with HIV.

I have been in a relationship with the same person now for over eight years and he is HIV negative. In our first couple of years together we often talked about the risk of transmission of the virus. These days it is just something we have naturally incorporated into our lives. Safe sex is not an option, it is an essential part of our lives together. There is no way we would risk the transmission of HIV from me to him or of any other sexually transmitted infections between the two of us.

However positive prevention to me is more than just safe sex. My view of positive prevention is now a holistic one that incorporates not only the prevention of the virus transmitting from me but also keeping myself healthy in terms of HIV. I do this by having regular health check-ups and blood tests and taking my antiretroviral medications as prescribed. The aim is to keep my immune system functioning as well as possible and keeping the virus at bay as seen by an undetectable viral load. However, I see my regular health checks as more than just a check of how my body is coping with HIV; it is also about my overall health status. I see a friendly doctor, who besides having expertise in HIV medicine is also a general practitioner, someone who can work with me to look after my whole well-being.

Living long-term with HIV brings the added challenges (or bonuses depending on how you look at it) of 'older age.' Whereas once I thought there was not such a need to worry about reaching fifty, now that is a real possibility (I am turning forty-seven this year!). So issues like a having healthy diet, maintaining good mental health, regular exercise, and giving up smoking become important issues. I now see those things as an integral part of positive prevention, keeping myself healthy, along with good HIV care. I gain much of my inspiration for my own wider view of positive prevention from my many positive friends, who give me the inspiration, ideas, and advice when needed on how to live my life to fullest.

Robert Baldwin

Where do we go from here with positive prevention?

The consultative process that began in early 2008 has clarified many points of agreement and enabled the drafting of a definition focused on people who know their positive status and the provisional set of positive prevention services above. At the same time, the process uncovered several areas where definitive statements are not yet possible. In some cases this is because people living with HIV are diverse, with vastly different perspectives and experiences, and agreement has not yet been reached on every issue. In other cases, it is because more evidence is needed before a determination can be made. Four significant remaining questions are:

- How can people who know their positive status get more involved and define the political agenda for positive prevention?
- What role will new prevention technologies play in promoting the health of people living with HIV?
- To what extent does being on antiretroviral therapy with no viral load protect against HIV transmission?
- What are the real risks to an HIV-positive person of being infected with another strain of the virus?

Involving people who know they are positive

The need to involve people living with HIV in HIV-related programming has been widely acknowledged, if not always honored in practice. When it comes to positive prevention, however, the specific activities that should be undertaken by people living with HIV have not yet been agreed upon. For practical purposes, leadership in positive prevention must come from those who know they are positive, since those who are unaware of their status will not realize the need to practice positive prevention.

Consultation conversations made it clear that many people living with HIV have not heard of positive prevention or do not understand what it means.^{xiii} The first important, concrete role that positive people can play is to define positive prevention and advocate for this definition to shape policies and programs. This working paper, and the consultative process that informed it, is a step in this direction. People living with HIV must also take the lead in sharing this definition with their peers and encouraging involvement in positive prevention at the personal, community, national, and international levels.

Better systems can also be developed for people who know they are living with HIV to provide practical guidance and support to their peers, from treatment adherence counseling to exercise buddy systems to

help with disclosure. Special efforts must be made to reach out to members of marginalized groups who are living with HIV to become active advocates and counselors as well as program participants.

New prevention technologies

A great deal of prevention attention and funding has been dedicated in recent years to “new prevention technologies,” including vaccines, microbicides, and male circumcision. These technologies are currently aimed at preventing new HIV infections, and as a result clinical trials and interventions are focused among HIV-negative people. We need more research into how these new prevention technologies can be used effectively by people living with HIV to maintain their own health and prevent transmission. There is a particular need to develop prevention methods that are female-controlled and do not rely on the consent or cooperation of a sexual partner.

People living with HIV strongly support the development of new prevention technologies.^{xliii} At the same time, they stress that HIV-positive people must be involved in this research at multiple levels. People living with HIV are among the best positioned to advise on the ethical treatment of clinical trial volunteers, particularly volunteers who become HIV-positive during the course of a trial. It is also important to ensure that any vaccine or microbicide that becomes widely available is safe for HIV-positive people. Even if a product is designed and labeled for use only by people who are HIV-negative, most people are not aware of their status and may turn to such a product for protection without realizing they are already living with HIV.^{xliiv}

Further, attention should be paid to the potential benefits of new prevention technologies for people living with HIV. For example, a therapeutic vaccine could be developed that would stop or slow the progression of HIV in people who are HIV-positive.^{xlv} A bi-directional microbicide could help a woman living with HIV to protect her HIV-negative partner from infection.^{xlvi} While vaccines and microbicides do not yet exist, and it makes sense for current research efforts to focus on determining whether HIV transmission can be effectively prevented by such technologies, their applicability for people living with HIV must also be considered throughout the development process.

It is also important to recognize that new technologies alone will not end the epidemic. The very factors that now make people vulnerable to HIV infection – poverty, gender inequities, racism, homophobia – will also likely affect access to and use of new prevention technologies. The struggle against human rights abuses must continue hand-in-hand with scientific research.

The protective effects of antiretroviral therapy and no viral load

Lowering the viral load in the blood of a person living with HIV reduces the risk of transmitting HIV, and antiretroviral therapy can reduce viral load to undetectable levels. In practice, antiretroviral drugs

clearly work well to reduce the risk of a mother transmitting the virus during childbirth. It is therefore logical to think that antiretroviral therapy should also reduce the risk of transmission to sexual or drug-injecting partners.

However, the evidence in this area is not yet altogether clear. Some observational studies have shown a protective effect, but the magnitude of protection remains unknown.^{xlvii} In January 2008, a group of leading experts in Switzerland published a statement to say that people living with HIV who adhere to effective antiretroviral therapy, have a suppressed viral load, and do not have any sexually transmitted infections cannot pass on HIV sexually.^{xlviii} However, other experts around the world called this recommendation premature and warned that people living with HIV should continue to rely on condoms for protection.

This is a critical issue, as people living with HIV need to know to what extent they can rely on antiretroviral therapy to protect the health of partners as well as to promote their own health and well-being. A large-scale, randomized control study of serodiscordant couples (of the same or opposite sex) currently underway in Brazil, India, Malawi, South Africa, Thailand, and Zimbabwe may answer these questions, with results expected in 2013.^{xlix} Until the study is complete, clear information and counseling guidelines must be in place so that people on treatment *and* their HIV-negative partners understand the extent to which there is still potential risk of infection. There is some evidence that the perception that antiretroviral therapy is protective may lead to riskier behavior, equally among people who are HIV-positive and those who are HIV-negative.^l

However, it is also very important to note that people who are actually on treatment have not been shown to engage in riskier behavior, and in fact people who adhere well to treatment regimens also report safer behavior.^{li} Treatment literacy campaigns can help people living with HIV to seek out and adhere to treatment, build social support for treatment access, and encourage safer sex among everyone in the community.

In addition, some people living with HIV are non-progressors, who maintain low or no viral load even though they are not on antiretroviral therapy. These positive people, too, need better evidence on their transmission risk and what they need to do to protect themselves and their partners.

The risk of “reinfection”

Many positive prevention programs stress the need for people living with HIV to avoid becoming infected with another strain of the virus. Because a new virus strain may be resistant to some existing antiretroviral drugs, particularly to the drugs that are most commonly used and easiest to tolerate, and because infection with multiple strains can lead to more rapid disease progression, couples in which both partners are HIV-positive have been urged to always use condoms.

However, the precise risks of reinfection (or superinfection) are not clear. Very few cases of reinfection have been identified.ⁱⁱⁱ Further, when it does occur, reinfection seems most likely to happen at the early stages of infection when viral loads are very high.ⁱⁱⁱⁱ Yet people who have only recently become HIV-positive are the least likely to be aware of their status, and thus the least likely to be reached by messages about reinfection.

At the same time, many couples in which both partners know they are HIV-positive would prefer to have sex without condoms, either because they want to have a child or because they find unprotected sex more physically or emotionally pleasurable. Sexual intimacy is an important part of overall well-being, and thus of positive protection. People living with HIV need better information about the risks to their health of having unprotected sex (or sharing injecting equipment) with an HIV-positive partner, so they can make educated choices.

Conclusion

Positive prevention programs that do not focus on the health needs of people living with HIV run the risk of exacerbating stigma and discrimination. In the worst case, “[i]nstead of receiving compassion and support, people are judged by the virus they carry and the main objective is to contain HIV within the existing group of carriers.”^{11v} Or, in more clinical language, “...strategies for prevention in positives may exchange population-level benefits for risks borne primarily by individuals living with HIV-1.”^{1v}

A new approach is needed. It should be guided by people who know they are living with HIV and are in the best position to understand what services would improve the lives of HIV-positive people and enable them to effectively care for themselves and others. It should maximize the linkages between prevention, treatment, care and support – as enhancing quality of life requires interventions in all these areas. Designed holistically, positive prevention programs will protect the health and well-being of people living with HIV. In turn, more people will be willing to seek testing and more people living with HIV – those who already know their status and the 90 percent who do not currently know – will incorporate safer, healthier behaviors in their lives. In time, this will slow the epidemic.

Such a program must recognize that positive prevention is practiced by and for people who know they are positive. At the same time, positive prevention is linked to other preventive health care efforts, including efforts to prevent HIV transmission. Everyone is responsible for stopping the transmission of HIV, a theme echoed time and again when people living with HIV discuss positive prevention.

Everyone also has a role to play in making sure treatment is available, reducing stigma and discrimination, and reforming punitive and ineffective laws. In the words of people living with HIV in Tunisia, positive prevention will succeed “when everyone joins together for the same cause.”¹² In turn, successful positive prevention will benefit everyone.

¹² “quand tout le monde s’unie pour la même cause. »

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- ⁱⁱ California HIV Planning Group, *Prevention with Positives*, p. 16 (note 1).
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- ^{vi} <http://www.vivopositivo.org/portal/sitio/007.htm>
- ^{vii} In Canada, see Bognar C. Positive prevention primer: BCPWA prevention campaign will target people with HIV. *Living +*, September/October 2002, http://www.bcpwa.org/articles/prevention_primer.pdf. Programs in the United States include, for example, Positive Images and the POWER Program in Los Angeles, San Francisco's STOP AIDS Project, the UNITY Project (San Francisco, Los Angeles, Milwaukee and New York City), and HIV Stops With Me (Boston, Buffalo, Long Beach, New York City, Oregon and San Francisco).
- ^{viii} *Séropositivité, vie sexuelle et risque de transmission du VIH*. Paris, ANRS, 1999.

^{ix} Janssen RS et al. Serostatus approach (note 4).

^x The positive prevention recommendations of AHP are described in CDC, Incorporating HIV prevention (note 4).

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^{xii} *Positive Prevention: Prevention Strategies for People with HIV/AIDS*. Brighton, UK, International HIV/AIDS Alliance, 2003.
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^{xvi} *Intensifying HIV prevention: a UNAIDS policy position paper*. Geneva, UNAIDS, 2005, p. 25.

^{xvii} *Practical Guidelines for Intensifying HIV Prevention: Towards Universal Access*. Geneva: UNAIDS, 2007.

^{xviii} *Essential Prevention and Care Interventions for Adults and Adolescents Living with HIV in Resource-Limited Settings*. Geneva, World Health Organization, 2007.
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^{xxi} Jamaica JAS

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^{xxiii} Jamaica JAS

^{xxiv} Algeria

^{xxv} Kenya

^{xxvi} Jamaica, Lebanon, Morocco, Bahrain, Mexico, Canada

^{xxvii} Lebanon, Tunisia, Mexico

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^{xxix} Jamaica JN+

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^{xxxiv} *Towards Universal Access: Scaling up priority HIV/AIDS interventions in the health sector*. Geneva and New York: World Health Organization, UNAIDS and UNICEF, 2008.
http://www.who.int/entity/hiv/pub/towards_universal_access_report_2008.pdf.

^{xxxv} Stigma is mentioned in nearly all discussions of positive prevention. Certain reports, including those from organizations of people living with HIV and the reports from the Alliance and the HIV Prevention Working Group, make specific recommendations around combating stigma.

^{xxxvi} Shapiro and Ray, *Sexual health*, p. 72 (note 5).

^{xxxvii} Positive Prevention: Draft Position Statement. *Health DevNet*, 2008,
<http://healthdev.net/site/post.php?s=1892>.

^{xxxviii} See Auerbach J. Principles of positive prevention. *Journal of Acquired Immune Deficiency Syndrome*, 2004;37(Supplement 2).

^{xxxix} PLAID Barbados.

^{xl} Shapiro and Ray, *Sexual health*, p. 72 (note 5).

^{xli} Mermin J et al. Developing an evidence-based, preventive care package for persons with HIV in Africa. *Tropical Medicine & International Health*, 2005;10(10), pp. 961-970.

^{xlii} Toronto, Ottawa, New Jersey, Kenya

- ^{xliii} *Microbicides and HIV Positive Women*. London: International Community of Women Living With HIV/AIDS and Positively Women, 2004. http://www.icw.org/tiki-download_file.php?fileId=108.
- ^{xliv} Positively Women, International Community of Women Living with HIV/AIDS, Global Network of People Living With HIV/AIDS, National Association of People with AIDS and Global Campaign for Microbicides. *HIV Positive Women and Microbicides*. Global Campaign for Microbicides, 2007. <http://www.global-campaign.org/clientfiles/FS7-PositiveWomen-March07.pdf>.
- ^{xlv} Auerbach, Principles of positive prevention, p. S123 (note 38).
- ^{xlvi} Positively Women et al., *HIV Positive Women*, (note 44).
- ^{xlvii} McClelland and Baeten, Reducing HIV-1 transmission, p. 163 (note 33).
- ^{xlviii} Vernazza P et al. Les personnes séropositives ne souffrant d'aucune autre MST et suivant un traitement antirétroviral efficace ne transmettent pas le VIH par voie sexuelle. *Bulletin des Médecins Suisses*, 2008:89(5), pp. 165-169, http://www.saez.ch/pdf_f/2008/2008-05/2008-05-089.PDF.
- ^{xlix} HIV Prevention Trials Network. *HPTN 052: A Randomized Trial to Evaluate the Effectiveness of Antiretroviral Therapy Plus HIV Primary Care versus HIV Primary Care Alone to Prevent the Sexual Transmission of HIV-1 in Serodiscordant Couples*. http://www.hptn.org/research_studies/HPTN052.asp; AIDS Vaccine Advocacy Coalition. *HIV Prevention Research: A Comprehensive Timeline*. <http://www.avac.org/timeline-website/index.htm>.
- ⁱ Shapiro and Ray, Sexual health, p. 78 (note 5).
- ⁱⁱ Shapiro and Ray, Sexual health, p. 78 (note 5).
- ⁱⁱⁱ Smith D, Richman DD and Little SJ. HIV Superinfection. *The Journal of Infectious Diseases*, 2005:192, pp. 438-444.
- ⁱⁱⁱⁱ West GR et al. Focusing HIV prevention on those most likely to transmit the virus. *AIDS Education and Prevention*, 2007:19(4).
- ^{liv} Moody K, Positive prevention, p. 2 (note 15).
- ^{lv} McClelland and Baeten, Reducing HIV-1 transmission, p. 165 (note 33).