

How Consultations by People Living with HIV Drive Change and Shape Policies, Programs and Normative Guidelines

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People living with HIV are increasingly involved in shaping HIV responses and their collective expertise and competencies are informing the revision and/or development of normative guidelines and policy frameworks. Recent consultations for the revision of the WHO's ART Guidelines and the conceptualization of a new 'positive prevention' framework – Positive Health, Dignity and Prevention – demonstrate how people living with HIV are transforming their individual realities into global policy dialogue. Their diverse voices and experiences are gathered systematically using different methodologies and consolidated into recommendations for advocacy. This approach not only facilitates the development of credible, acceptable and effective guidelines, it also enhances ownership of the process, enables people living with HIV to hold their governments accountable and forms the basis for sustained advocacy.

INTRODUCTION

Since the early years of the HIV epidemic, HIV responses have been propelled by social movements of people living with HIV and populations most affected by HIV. Their advocacy made it a global health imperative to involve and recognize the rights of those most affected by HIV.¹ In 1983 a small group of people living with HIV met at a gay health conference in Denver, Colorado and wrote a document now known as the Denver Principles, which defined the rights and responsibilities of people with HIV. The notion of self-empowerment at a time of great fear and hysteria was profound and influential, and this concept was incorporated into a broader global movement towards the greater and meaningful involvement of people living with HIV (GIPA/MIPA). In 1994, 42 countries signed the Paris Declaration, formally recognizing the call for the active and meaningful involvement of people living with HIV in the HIV response.²

Whilst there is international recognition that the involvement of people living with HIV needs to inform guidance on programs that affect people living with HIV, operationalization of consultative processes by people living with HIV remains undefined and haphazardly utilized. A more structured and systematic engagement of the Global Network of People Living with HIV (GNP+) and other organizations representing and advocating for people living with HIV began in 2009 by contributing to the revision of normative guidelines and frameworks that inform HIV prevention, treatment, support and care policies and programs.

This paper reflects on two initiatives (April 2009 – June 2010) where unique consultative processes between communities of people living with HIV and normative agencies have shaped policies, programmes and normative guidelines. Harnessing the lessons learned in the processes and methodologies of engaging with people living with HIV as well as collaboration with normative agencies can support further engagement and begin “defining” what it means to effectively engage people living with HIV through consultations. The first example is the 2009 revision of the WHO *Recommendations for Antiretroviral Therapy for HIV Infection in Adults and*

Adolescents (ART Guidelines), during which GNP+ led a series of electronic and face-to-face consultations resulting in recommendations which helped shape these ART Guidelines. The second example is a consultative process in the reframing of 'positive prevention' into the more holistic, human rights-based conceptualization of "Positive Health, Dignity and Prevention" leading to a paradigm shift on the content of these two policies and programs aimed at people living with HIV.

These strategies and techniques can be adapted for further consultation with people living with HIV as a way of translating individual realities into global policy dialogue, providing expertise and perspective vital for the credibility, relevance, acceptability and effectiveness of global HIV guidelines, policies and programs.

This paper focuses both on the process of conducting consultations and the quality of the results collected.

METHODS

While involving people living with HIV in global policy processes is not new, the consultative processes described in this paper highlights *structured* methodologies for gathering and synthesising multiple and diverse voices. The two cases chosen reflect a range of methodologies in collecting experiences on two thematic areas. The first example involves people living with HIV contributing to an existing global process, while the second involves people living with HIV setting an agenda. Evidence was drawn from consultation reports, which were developed following each activity.

REVISION OF ART GUIDELINES

Process for Engagement

The consultations led by GNP+ involved a process initiated by the World Health Organization (WHO), which also involved other civil society organizations, researchers, scientists and policymakers. GNP+ conducted two technical consultations and one e-consultation. The consultations sought to gather rich, meaningful input from people living with HIV about what they want and need from their treatment programs based on their experience and expertise concerning ART. Furthermore, it sought to gather insights on the needs and knowledge of people living with HIV beyond their bio-medical and health service-seeking experiences. In other words, the process sought to gather the invaluable knowledge about where treatment is taken; where sexual and reproductive health needs arise; where vulnerabilities to gender inequalities occur; and where discrimination based on HIV-positive serostatus impacts people's lives.

The first technical consultation was held in partnership with the Treatment Action Campaign held during the International AIDS Society Conference in Cape Town on 20 July 2009 (30 participants; 65% women, 35% men; representing 13 countries; mean age 40 years). The second consultation was in partnership with the Asia Pacific Network of People Living with HIV (APN+) held during the International Congress on AIDS in Asia Pacific on 12 August 2009 (23 participants; 26% women, 74% men; representing 8 countries; mean age 39 years). Participants had a diverse range of treatment experience — from those who were not yet on ART, to some who were on their first-line regimen and some who had been on different treatment regimens for a long time.

In parallel to the above two consultations, GNP+ held an e-consultation over three weeks (27 July – 16 August 2009), hosted by NAM on their website aidsmap.com (317 advocates and activists living with HIV invited to participate via email; 40% of invitees registered, of whom 52% posted comments; participants had been selected based on previous engagement with GNP+ consultations). Participants came from 36 countries representing all six WHO regions: Americas (13 countries), Africa (9), Western Pacific (5), Europe (4), Eastern Mediterranean (3), and South-East Asia (2). Following initial invitations, participants received weekly emails inviting them to share their experiences and opinions on three specific topic areas: how people living with HIV felt about treatment and what they expected from ART; balancing the tension between quality and equity of HIV care; and the importance of a human rights-based approach to treatment when used as a prevention tool. All six emails included the link to the e-consultation website (<http://www.aidsmap.com/gnp+>) as well as a personal password linked to the individual's email address. The e-consultation was conducted in English and moderated by a GNP+ consultant living with HIV. Participants from Algeria, Bolivia, Morocco and Peru posted comments in their native tongue, namely French or Spanish: the moderator coordinated the provision of an English translation following their post. Several participants contributed via email (due to connectivity challenges and insufficient IT literacy): the moderator posted their comments on their behalf. The moderator regularly monitored the discussions to ensure that the posts were applicable to the subject; to answer any specific questions; to summarize the discussions and stimulate further reactions, and to suggest further areas of discussion within each question.

Prior to commencing the consultations, the questions employed were developed and reviewed by GNP+ and its partners, including WHO, to ensure that they were clear, that there were no gaps in coverage of all aspects of the guidelines, and that the language was appropriate (e.g., for non-medical experts). Furthermore, partnering with regional organizations enabled GNP+ to ensure that questions were adapted to the regional context.

The timescale to conduct these consultative processes was a challenge because they involved a series of activities that included developing partnerships; designing context-specific questions; promoting activities; and conducting the consultations. Additionally, the decision to undertake a qualitative piece of work meant it was important to focus on a carefully selected set of respondents with a diverse and balanced range of experiences and expertise.

RESULTS

People living with HIV valued the consultative processes and the opportunity to contribute to a more patient-centred version of the ART Guidelines.

One of most important points to emerge from this e-consultation was the broad consensus that people living with HIV must be educated and empowered about their treatment-related options in order to make a joint decision with their clinician, and that treatment should begin:

- When the individual is ready;
- Based on the individual's overall health rather than focusing solely CD4 count criteria;
- And that the individual, rather than the virus, should be the focus of treatment and care.

CD4 count criteria for starting treatment should be in line with current scientific knowledge of best outcomes, at 350 cells/mm³. There was also broad consensus that d4T (stavudine) be removed from the list of recommended medications due to its toxicity profile, and that tenofovir be recommended in its place.

The above recommendations were all adopted in the revised version of the WHO's ART Guidelines.³ Beyond setting (medical) standards for HIV treatment and care, people living with HIV were able to provide the context to the scientific discussions that informs not only the provision of treatment but also the quality of care. Most notably, the recommendations from the consultations provided insight into, and informed how, ART programming can be effective. For example, they emphasised that people living with HIV want care and treatment programmes of the highest quality, but they also prefer them to be as simple and unobtrusive as possible. They do not want programmes to require people who are stable on treatment to come into the clinic unless it is absolutely necessary. ART programmes require information about the preferences of users if they are to be effective in addressing their needs. This invaluable knowledge, even if it may not be found in the revised ART Guidelines, forms the basis for advocacy for networks of people living HIV.

The process also provoked discussion and provided additional recommendations to inform global debate. For example, the results of the process also highlighted that the WHO should highlight the link between treatment and prevention, in particular the potentially beneficial effect of ART on infectiousness, on both a population and individual level. The experiences and views gathered from these consultations can inform the debate on treatment for prevention, enable linkages with combination prevention – which accepts that focusing primarily on behavioral change is overly simplistic and addresses societal and structural issues as well as embracing new biomedical prevention tools such as circumcision, PreP, microbicides and ART's preventative effects – and address the prevention needs of people living with HIV more generally.

POSITIVE HEALTH, DIGNITY AND PREVENTION FRAMEWORK

Process for Engagement

Structured consultations with people living with HIV on HIV prevention started in Monaco in January 2008 as a prelude to a summit entitled LIVING 2008: The Positive Leadership Summit, which took place before the International AIDS Conference in Mexico in July - August 2008. The sessions on 'positive prevention' at LIVING 2008 generated much debate about the role of people living with HIV in HIV prevention. Participants argued that 'positive prevention' should not be imposed on people living with HIV but should be defined and owned by people living with HIV. Additionally, there was recognition that stigma and discrimination needed to be addressed within the context of 'positive prevention' in order for the concept to be relevant to people living with HIV.⁴

Subsequently, GNP+ and the Joint United Nations Programme on HIV/AIDS (UNAIDS) co-organized an International Technical Consultation in Tunisia in April 2009 where participants agreed on a new concept: Positive Health, Dignity and Prevention which moves away from treating people living with HIV as passive targets of prevention messages towards recognizing them as active participants in the HIV response. The meeting was attended by 50 participants from 28 countries on six continents, representing networks of people living with HIV, development agencies,

civil society organizations, country implementers, multilateral and UN agencies and donor agencies. More than half of the 50 participants were people living with HIV.⁵

Positive Health, Dignity and Prevention is the new name for a revised concept of HIV prevention for and by people living with HIV, formerly known as 'positive prevention'. It emphasizes that responsibility for HIV prevention should be shared, and that policies and programs for people living with HIV should be designed and implemented with the meaningful involvement of people living with HIV.

Positive Health, Dignity and Prevention focuses on improving and maintaining the dignity of the individual living with HIV, which has a positive impact on that individual's physical, mental, emotional and sexual health, and which, in turn, creates an enabling environment that will reduce the likelihood of new HIV infections.

By linking together the social, health and prevention needs of individuals living with HIV within a human rights framework, Positive Health, Dignity and Prevention results in a more efficient use of resources with outcomes that are responsive to the needs of people living with HIV, with additional benefits for their partners, families and communities.

Later in June 2009, the Asia-Pacific Network of People Living with HIV (APN+) held consultations on Positive Health, Dignity and Prevention in Bangkok during their Annual General Meetings. In August 2009, a meeting of 37 participants convened by the Indonesian Network of People Living with HIV (JOTHI), APN+, GNP+ and UNAIDS, sought to explore programmatic, policy and research health and prevention priorities for people living with HIV within the Asia Pacific region and to agree on ways to move Positive Health, Dignity and Prevention forward. Consultations were also held in Casablanca with 33 participants representing a range of organizations within the Francophone Community.

GNP+ and UNAIDS have shared the outcomes of the series of consultations on Positive Health, Dignity and Prevention with a range of partners. Additionally, GNP+ and UNAIDS met with several US Government Agencies – the Centre for Disease Control and Prevention, Department of Defense and US Agency for International Development – to explore opportunities to work together to translate the concept of Positive Health, Dignity and Prevention into practice.

Finally, structured telephone interviews with networks of people living with HIV, development agencies, governments and donor agencies were conducted by regional partners to document good practice and gather case studies for the development of a framework on Positive Health, Dignity and Prevention.⁶

RESULTS

The consultative processes highlighted that people living with HIV have always been powerful and passionate advocates for evidence-informed responses to HIV, including HIV prevention. The technical consultation in April 2009 was an opportunity to engage networks of people living with HIV, civil society, government agencies, UNAIDS cosponsors, international donors and development agencies around an inconsistent and ill-defined concept of HIV prevention for people living with HIV. Prior to this, most policies and programs have been designed, for the most part, without the meaningful involvement of people living with HIV.

Through the consultative processes, participants agreed that policies and programs that are designed by people living with HIV, and treat people living with HIV humanely and focus on their health holistically – as opposed to being treated as patients who are potential vectors of transmission – are likely to have a greater acceptance from people living with HIV. Such policies and programs will also help to reduce HIV-related stigma and discrimination, resulting in numerous beneficial effects for people living with HIV (including the many people living with HIV who are unaware of their status), their partners, families and communities.

The new framework is the first step towards operationalizing Positive Health, Dignity and Prevention. It will be used to inform the development and implementation of policies and programs that are developed, led, monitored and evaluated by people living with HIV. It is envisaged that regional and/or country-level programmatic guidelines will be drawn up that incorporate the policy model into practical programs linking treatment with care, support and prevention; linking the clinical and medical with psychosocial, socio-cultural, political and development realities; and linking all within a human rights framework that advocates for supportive policies.

The framework is driving change because people living with HIV have an entry point to engage in the global debate on HIV prevention. It is also a guiding document for UN agencies, the public and private sectors, donor and multilateral agencies. It outlines how to support and nurture the leadership of people living with HIV as they move towards the ownership of programs that allow them to live in dignity, maintain or improve health, and be empowered to make choices that have a beneficial impact for themselves and their partners, families and communities.

DISCUSSION

People living with HIV are driving change and shaping global policies and programmes. Engagement in the revision of the ART Guidelines and the development of the framework on Positive Health, Dignity and Prevention have been opportunities for people living with HIV to input into global policy dialogue by sharing their experiences and perspectives in a systematic and structured way.

Such experiences and perspectives have shown that people living with HIV are advocating for programmes that place more emphasis on the individual's holistic needs rather a top-down medicalized approach that sees people living with HIV only as patients or potential vectors of transmission.

As people living with HIV were involved from the beginning of the process, there is a greater ownership of the outcomes, facilitating continuous engagement and sustained advocacy on the issues, including a greater commitment to disseminating information, gathering further input from communities and using tools to lobby governments and policymakers to support processes in-country.

The consultative process highlighted the different strategies which networks are using to engage with their constituents for global processes. They also highlighted possibilities to identify regional and general recommendations.

Networks are continuously improving their ability to reach and engage people living with HIV in processes that directly impact their lives. People living with HIV have experiences and views to share that can inform the development of programs and policies that are accessible, relevant and responsive to their needs. This consultative approach will be further refined and replicated for future WHO guideline development and it is hoped that there will be other opportunities for other normative agencies to utilize such an approach.

REPRESENTATION

The diversity of the HIV epidemic makes it challenging to represent a full range of experiences and needs. However, the active and meaningful engagement of diverse groups of people living with HIV, particularly those from socially marginalized groups, is key to developing responsive policies and programs. Identifying and representing problems remains a challenge within the PLHIV movement with processes led by national, regional and global networks sometimes criticized as non-transparent and undemocratic.⁷ The issue of representation raises questions about legitimacy and the extent and coverage of the representative voice.⁸ Representatives may not convey the voice of their constituency or only the voices of a select few may be heard. Therefore consultative processes that are developed and coordinated with relevant regional partners and groups of key populations - defined by UNAIDS as including indigenous people, men who have sex with men, migrants, people who use drugs, prisoners, refugees, sexual minorities (including intersex and transgender people), sex workers, women and girls, and young people – are essential in identifying appropriate means of involving a diverse range of people living with HIV to share and represent their issues in global fora.⁹

Capturing Regional Differences and Diversity

The consultative processes not only provided an opportunity to develop general recommendations but also provided an opportunity to capture regional specificities. In the consultation for the ART Guidelines, people living with HIV discussed the benefits and tradeoffs of WHO recommending starting ART earlier with more expensive regimens. Although participants from sub-Saharan Africa, especially, were concerned about current and future levels of funding on medication access issues, many advocates argued that the guidelines could be used as a tool for activism amongst people living with HIV, and it that it was up to people living with HIV and civil society to ensure that governments and funders see the long-term cost-effectiveness of starting treatment earlier with better medications. While the process nurtured ownership of the guidelines and process, in similar processes in the future, people living with HIV would like to explore their role in operationalizing the normative guidance through initiatives which translate the guidance into programming and support service provision and quality assurance.

In the consultations undertaken by GNP+ regarding the new framework, 'Positive, Health Dignity and Prevention' it has become clear that the framework (including the term) may need to be adapted when translated or based on regional specificities. Consultations amongst representatives of people living with HIV in the Asia-Pacific region preferred the term 'Positive Health', as the concept of 'dignity' was not easily transferable in some Asia-Pacific countries and the term 'prevention' continues to have negative connotations. Similarly, consultations amongst representatives of people living with HIV in French-speaking Africa requested a review of the word 'Dignity,' as the meaning of this word in English – as it relates to human rights – may not mean the same in some French-speaking countries on the African continent. Developing a common language for broader concepts, such as Positive Health, Dignity and Prevention, is the ultimate goal, and it is especially important to consult people living with HIV about concepts and terms used to describe policies and programs that affect them as concepts affect how people feel about themselves and impacts their ability to maintain their own health and wellbeing.

CONCLUSION: FROM 'GREATER AND MEANINGFUL INVOLVEMENT' TO POLICY AND PROGRAMMATIC LEADERSHIP

Despite international recognition about the importance of the role of people living with HIV, this has not translated into systematic means of gathering the views of significant numbers of people living with HIV nor guidelines for identifying how these views should be represented in global policy debates. The consultative processes described in this paper provide examples of mechanisms for people living with HIV to share their lived experiences and for GNP+ to gather the responses of people living with HIV to develop a strong and relevant evidence base for advocacy. These consultative processes have led to two very different outcomes - the support of WHO's ART guidelines and the creation of a new paradigm of prevention for and by people living with HIV. The framework for the latter goes beyond GIPA principles to place people living with HIV at the centre of determining which policies and programs support and enable them to live healthy lives and make healthy choices. One of the principles of Positive Health, Dignity and Prevention is that all policies and programs affecting people living with HIV should include – and ideally be led by – people living with HIV in their development, implementation, and monitoring and evaluation. While the principles of HIV-related self-determination are as important and relevant today as they were in Denver almost three decades ago, Positive Health, Dignity and Prevention reconfirms these principles and reframes them to fit within the context of a mature HIV epidemic as we move towards concrete strategies that strive to achieve their fulfillment.

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¹ International HIV/AIDS Alliance and Global Network of People Living with HIV. Good Practice Guide: Greater Involvement of People Living with HIV (GIPA). International HIV/AIDS Alliance/GNP+, 2010.

² The Paris Declaration, 1994.

http://data.unaids.org/pub/ExternalDocument/2007/theparisdeclaration_en.pdf

³ World Health Organization. *Rapid advice: antiretroviral therapy for HIV infection in adults and adolescents*. November 30, 2009.

⁴ LIVING 2008 Partnership. LIVING 2008 Summit Themes: Positive Prevention

<http://www.living2008.org/images/stories/positive%20prevention%20en.pdf>

⁵ GNP+, UNAIDS. Positive Health, Dignity and Prevention. Technical Consultation Report. Amsterdam, GNP+. 2009.

http://www.gnpplus.net/images/stories/PHDP/PHDP_MR_EN_newlogo_v2.pdf

⁶ GNP+, UNAIDS. 2010. Policy Framework: Positive Health, Dignity and Prevention. Amsterdam, GNP+ (forthcoming).

⁷ Revitalising the Global Movement of People Living with HIV Think Tank Meeting. Nairobi, Kenya, 28-30 November 2005. http://www.gnpplus.net/cms-downloads/files/Nairobi_meeting_report.pdf

⁸ David Stephens. Out of the shadows: the Greater Involvement of People Living with HIV/AIDS (GIPA) in Policy. Policy Working Paper Series No. 14. 2004

⁹ UNAIDS *Key Populations*.

<http://www.unaids.org/en/PolicyAndPractice/KeyPopulations/default.asp>