

Key findings and recommendations from consultations with people living with HIV

Developed by GNP+, ICW, ITPC and Young Positives

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Introduction

The WHO solicited the input of people living with HIV for the upcoming revision of the WHO *Recommendations for Antiretroviral Therapy for HIV Infection in Adults and Adolescents*. Four international networks led on consultations with people living with HIV:

- Global Network of People Living with HIV (GNP+)
- International Community of Women Living with HIV (ICW)
- International Treatment Preparedness Coalition (ITPC)
- Young Positives

Each network undertook different approaches to the consultative process:

- GNP+ organised two regional meetings alongside international conferences at the IAS 2009 in Cape Town, South Africa (30 people living with HIV from 13 countries) and ICAAP 2009 in Bali, Indonesia (23 people living with HIV from 6 countries). GNP+ also hosted an e-consultation with people living with HIV who are engaged in key GNP+-led activities (66 people living with HIV from 36 countries);
- ICW conducted three focus group discussions among women living with HIV in Botswana, Namibia (15 women living with HIV) and Swaziland (13 women living with HIV);
- ITPC developed a 30 question survey tool through its Treatment Monitoring and Advocacy Project. The tool was used in 42 countries and replies were received from a total of 417 people;
- Young Positives promoted the regional meetings organised by GNP+ and partners and participated in the e-consultation.

The networks valued the consultative processes and the opportunity to contribute to a more patient-centred version of the ART Guidelines. The results of the process highlighted that the WHO Guidelines should be based on the best, current scientific knowledge, focusing on a standard of care that all countries should strive to achieve. There was general agreement that WHO should recommend earlier treatment with more choice of better-tolerated drugs, because of both the cost-effectiveness of such an approach and the direct improvement of quality of life for people living with HIV. 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.

Key findings

Treatment education

There is broad consensus that people living with HIV must have access to relevant, comprehensive and accurate information to be able to make their own choices about when to start and change treatment as well as the benefits and disadvantages of different treatment options. Treatment education is essential for adherence, a critical factor in the sustainability of ART rollout. As part of treatment education, there is need for peer counselling and support as an intrinsic element of ART delivery.

Treatment options

In all consultations the benefits of starting treatment earlier was recognised. Participants stated that the ART Guidelines should recommend treatment be initiated at 350 CD4 cell counts. However, the ART Guidelines should advise pregnant women and people with HIV/TB co-infections to start treatment as soon as they are ready. While starting earlier may increase the number of people qualifying for treatment, in resource-limited settings, people often present quite late. If a person comes into a clinic with a CD4 cell count of 300, and is ready to start treatment then, it is important they have access, since it might be the only opportunity to get them into care. Additionally,

tenofovir should be recommended as part of first line regimen in place of d4T, which should be discouraged on account of its toxicity.

Side-effects, drug resistance and drug stock-outs

People living with HIV expressed fears about side-effects, drug resistance and drug stock-outs – factors that influence both their choice of when to start and change treatment and the long-term efficacy of their treatment regimens. While people living with HIV broadly recommend initiating treatment at a CD4 cell count of 350, individual readiness is essential. Clearer information about side-effects and drug resistance can inform the choices that people living with HIV make and their ability to adhere to treatment.

Monitoring

People living with HIV asserted that CD4 counts and viral load tests must be considered standard monitoring tools. They are ready to compromise on viral load monitoring frequency if it means that earlier treatment with better drugs could be offered to more people. Some also argued that resistance testing prior to starting treatment and following treatment failure was both necessary and cost-effective to prevent unnecessary treatment switches. People who are clinically stable may prefer fewer clinic visits and less intensive laboratory monitoring.

Co-infections

The consultations all emphasised the importance of providing information for people living with HIV on co-infections, such as TB, HBV and HCV, both before and during ARV therapy. This is particularly urgent for HCV among those engaged in high-risk behaviour. In addition to information, both universal testing and accessible and affordable treatment needs to be provided for all three infections, ideally at the location where people living with HIV receive their primary care.

Treatment for prevention

People living with HIV believe the link between treatment and prevention is important and urge WHO to highlight and clarify the role of treatment for prevention to ensure universal sustainable access to timely ART, encourage undiagnosed individuals to know their status and reduce infectiousness on an individual and population level. There is general agreement that the primary purpose of ART is for the health and wellbeing of people living with HIV, although its use to prevent vertical transmission to infants is an exception to this rule. In this case, however, the decision for a woman or her baby to take treatment should be made by the woman based on clear and balanced information.

Holistic health and wellbeing

People living with HIV, and women in particular, highlighted the importance of an effective broad service delivery package to complement ART programmes. Health assessments should include checking for liver/kidney dysfunction, diabetes, cancers and cardiovascular risk. Initiatives on nutrition and food security should be strengthened to promote the wellbeing of people living with HIV. Stigma and discrimination reduction programmes within communities and the health care setting are essential in fostering a supportive environment for people living with HIV.

Key recommendations

GNP+, ICW, ITPC and Young Positives recommend the following points to be included in the ART Guidelines:

1. People living with HIV must be educated and empowered to make their own choices about their options for treatment and care;
2. Treatment must be recommended when CD4 counts fall below 350;
3. Tenofovir should be part of a recommended first line regimen in place of d4T (stavudine);
4. People living with HIV must have access to regular CD4 counts and periodic viral load tests;
5. People living with HIV must have information about drug resistance and, if possible, access to drug resistance testing. WHO needs to consider the role for resistance tests as more treatment options become available;
6. People living with HIV must have access to more information on co-infections, such as TB, HBV and HCV, both before and during ARV therapy, as well as affordable access to treatment and monitoring;
7. Highlight and clarify the role of treatment for prevention;
8. Promote holistic health and wellbeing of PLHIV to render ART programmes more effective.