Consultation on WHO ART Guidelines
A Grassroots Perspective of HIV+ Individuals*

August 2009
Presented at Amsterdam

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Community consultation on issues related to revisions of WHO ART guidelines
International Treatment Preparedness Coalition - Project report
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Summary
This community consultation was part of a global effort – supported by the WHO - to solicit input and suggestions from communities affected by HIV, and in particular PLHIV, for the upcoming revision of the WHO Recommendations for Antiretroviral Therapy for HIV Infection in Adults and Adolescents. The 30 question survey tool was used in 42 countries, and replies were received from a total of 417 people. The survey results indicate that most PLHIV have a high degree of awareness of basic issues related to ART, such as side-effects and the need for strict adherence, but that they also face a number of barriers, and in some cases lack sufficient access to services and information. Barriers such as drug stock-outs and limited access to viral load or opportunistic infection screening, as well as affordable treatment for Hepatitis B and C, were all identified as issues that could be addressed in the newly revised guidelines. In addition, universal access to information regarding TB, HBV and HCV co-infection (including testing and treatment information) was identified as a common challenge for the health of PLHIV in developing countries. Finally, with an increasing number of PLHIV on ARVs, the issue of drug resistance was not sufficiently understood by respondents, nor was testing accessible for most respondents, a critical gap in service access given the current lack of affordable second line ARV drugs.

Survey Design
Based on the key issues raised in the initial call for proposals, ITPC designed a survey tool containing 30 questions. The aim was to collect opinions and feedback on a variety of real-life decisions and issues facing PLHIV, as much as possible addressing all of the issues discussed in the original TOR. As many people at the community level – who are ultimately those who will be affected by revised treatment guidelines - are not familiar with the technical terms, the questionnaire tried to expand and simplify each of the original issues. The full survey is included in Annex 3 of this report.

Survey Planning and Implementation
This survey was designed and carried out through ITPC’s Treatment Monitoring and Advocacy Project [TMAP], but relied heavily on the networks of mostly PLHIV-led NGOs and CBOs that have received support through ITPC’s Collaborative Fund project. Both staff and volunteer advisors worked to design and revise the survey, with all regional coordinators involved in discussions. ITPC/Collaborative Fund Regional Coordinators in Africa, Asia, Latin America and the Caribbean took the lead in distributing and collecting surveys at the
The survey was conducted in five of ITPC’s African regions, one Asian region, and two American regions: Latin America and the Caribbean. [See Annex 2 for a list of project coordinators, advisors and regional participants]

In addition to English, the survey was translated into four languages to be used in different countries: Spanish, French, Portuguese and Swahili. While this added a difficult and time-consuming step to the total process, it was essential in order to reach more than just English-speaking communities. With the exception of one survey from Hong Kong, all respondents were from lower or middle income countries.

The consultation was carried out at by ITPC regional coordinators, each of whom were responsible for translation into local languages, distribution of surveys, conducting face-to-face meetings, and working with local PLHIV community members to ensure that surveys are fully understood and completed. Individual community members then completed their own surveys, which were collected by regional coordinators before being returned to the overall project coordinator. Focus group discussions were not possible due to a lack of time and funds to host such meetings.

Survey Results

Survey respondents were largely African, reflecting both the strength of the ITPC networks there and the motivation of community members to have their voices heard. Respondents were disproportionately female in Africa, and disproportionately male in Asian and American regions. Nearly two-thirds of respondents were from urban areas.

I. Overview of survey respondents

Countries involved: 42 Countries (see details below)
- Africa (71%) – 295 respondents
- Asia (7%) – 29 respondents
- Latin America/Caribbean (22%) – 93 respondents

Total Surveys collected: 417

Gender and demographic breakdown of respondents:
- Gender: 154 Male (38%), 251 Female (62%) and 2 Other
- Age: Average age was 36  (Min = 19, Max = 59)
- Urban/Rural = 63% / 24% (13% reported being “in between” urban and rural)

Treatment history of respondents:
- Average year discovered HIV status: 2002
- Average gap before going on ARVs: 2.5 years
Table 1: Geographic Beakdown of survey respondents

<table>
<thead>
<tr>
<th>West Africa</th>
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<th>Central Africa</th>
<th>SE Asia</th>
<th>Latin America</th>
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Women + Children | Caribbean | Sri Lanka | 1 | Peru | 2 |
Rwanda | 12 | Trinidad | 10 | Malaysia | 1 | Argentina | 1 |
Uganda | 33 | Haiti | 20 | Total | 14 |
Malawi | 21 | Jamaica | 21 |
Nigeria | 14 | Puerto Rico | 11 |
Total | 80 | Guyana | 17 |
Total | 79 |

II. Detailed replies to survey questions

Overall attitudes towards ART

As would be expected, the main reasons for seeking ART were 1) to stay alive and 2) to improve health or quality of life, with 79% and 71% of respondents citing these reasons. (Note that each respondent provided the two main reasons for their seeking ART).

Side effects, the need for strict adherence, and stood out as the two most difficult things about being on ARVs (68% and 53% respectively), but a significant number of respondents included other replies:
• pill burden (30%)  
• Lack of support from friends, family, and peers (24%)  
• Fear of drug stock-outs (27%)

There were significant regional variations in these replies, with 100% of respondents in Southeast Asia citing “drug stock-outs” (compared with only 10% in the Caribbean) and 78% of respondents in the “women and families (West Africa)” region citing “lack of support from friends, family and peers”, (compared with 0% in SE Asia).

Access to newer ARVs and ARV combinations

Though this survey collected insufficient data on actual regimens being used in different countries, there was strong agreement that the issue of access to ARV combinations including newer ARVs such as TDF and LPV/r is extremely important. 69% of respondents said the issue was “very serious”.

**Adherence and Adherence support**

66% of respondents thought that it was “very serious” problem to not have peer counseling available in the clinic/hospital where PLHIV receive their ARVs. 53% of respondents thought that it was “very serious” if somebody on ARVs doesn’t have dedicated people to help them adhere to the drugs.

**Side-effects and treatment interruptions**

46% of respondents said they had experienced “strong side effects” when initiating their ARV therapy, and 25% of those either stopped or switched their drugs. This indicates the need to ensure access to regular and high-quality monitoring for adverse effects of ARV therapy, including additional counseling and support (medical and peer) for those who must change treatment regimens.

**Early initiation of ARV Therapy**

There was clear agreement (66% of respondents) that early initiation of ARV therapy was desirable despite the risk of side-effects, and a similar majority (77%) felt that starting ARVs too late was a “very serious” problem.

Most respondents expressed concern or fear of side-effects with regard to early initiation of ARV therapy, with a small number expressing fear of drug stock-outs or ARVs becoming ineffective. In Southeast Asia, a high percentage (50%) of those who supported early initiation of ARV therapy expressed fear that, should they develop resistance to first line ARVs, there would be no second line available, making early initiation of ART a risky prospect. 100% of respondents from SE Asia also said that fear of drug stock-outs was one of the three hardest things about taking ARVs.

Of those who explained their support for early initiation of ART, most said they wanted to avoid opportunistic infections and try to continue leading a “normal life”.

Finally, while “early” was not explicitly defined (ie, CD4=350 was not mentioned), the basic issue is still the same – whether the benefits or early treatment outweigh the risks.

**ARV resistance**

36% of respondents said that ARV drug resistance was “little understood”, “not understood at all”, or not even discussed in their communities. Only 26% said the issue was “well understood”.

ARV resistance testing was reported to be available “in the country” by 37% or respondents, though only 18% replied that such testing was always available to PLHIV on ART.

There was strong understanding – though this may also be due to the survey sample and ITPC’s work on this issue – that stopping your ARVs for “many days or weeks” is an extremely serious problem (79% of respondents, compared to only 7% who said it was “moderately serious” or “not very serious”).

**TB testing, HIV-TB co-infection, and TB treatment**
TB testing was reported to be available as part of a “standard package of care and treatment” by only 56% of respondents, with more than a third (35%) saying it was not. When it is available, 79% of respondents said the testing was free, and 64% said it was offered at the same location as ARV treatment.

Treatment for TB was reportedly available in 75% of communities, with 81% of those responding that TB treatment is free of charge. However, a surprising 34% of respondents said they did not know if there were any entry restrictions for TB treatment, and 41% said they don’t know if 2nd line treatment is available for TB. These both point to a lack of TB treatment and TB education information being available to PLHIV. Indeed, 45% of respondents said that TB treatment education and information is not provided to those on ART.

On the topic of Drug resistant TB, 81% of respondents said that it was a problem in their communities, though only 16% said treatment was being provided. 22% said that “nothing or very little” was being done, and 32% said they didn’t know.

*Hepatitis-B and Hepatitis-C co-infection*

The availability of treatment for HBV and HCV is a cause for concern. Fewer than half (47% and 40% respectively) said that treatment was available, and fewer than half of those (45% and 43% respectively) said that it was available at the primary health level in their communities. A majority of respondents (56% and 71% respectively) said that treatment for HBV and HCV was too expensive and hard to afford for PLHIV.

Perhaps most worrying was the lack of information and understanding of HBV, HCV and HIV co-infection. Nearly half (46%) said that PLHIV are “rarely” or “never” given information about HBV and HCV, and only 7% said they are always given such information. Finally, 37% of respondents said that Hepatitis/HIV co-infection is “not understood” or “not discussed” in their communities, with another 25% saying it is “little understood”. Only 3% said the topic was well understood among their peers.

This clearly indicates an urgent need for both information and treatment to be made available to all PLHIV regarding HBV and HCV co-infection.

**Conclusions and Recommendations**

A number of conclusions can be drawn from this community survey:

First, treatment education works, and treatment literacy is essential for effective roll-out of treatment and care for PLHIV. It is clear that those in ITPC’s network are aware of the seriousness of not adhering to their treatment regimen (OR ITPC-CF grantees understand the importance of adhering to treatment). As part of treatment education (and related support), there is a clear need to have peer counseling when providing treatment.

Second, it is essential to provide more information on co-infections, such as TB, HBV, and HCV to PLHIV, both before and during ARV therapy. This is particularly urgent for HCV among those engaged in high-risk behavior. 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 PLHIV receive their primary care.

Third, two-thirds of respondents feel that it is a good idea to start ARVs early, mostly to avoid the onset of illness (OIs) and continue to lead a healthy and productive life. Many respondents raised the issue of discrimination, both in support of early treatment (to avoid stigmatizing OIs) and as a fear (of being discovered on ARVs).

Fourth, information about drug resistance and access to drug resistance testing are both seriously lacking. Even if resistance testing is not available, everyone going on ARV therapy should be fully informed about the risk of drug resistance (in addition to side-effects and other related issues). These services, along with a comprehensive package of regular diagnostic testing, counseling and support, should be universally available to all PLHIV, ideally at the point of primary health care provision.

**Barriers and challenges**

- Time was a major challenge, as organizing a consultation that really reaches grass-roots community members requires a lot of time.
- Language and translation capacity produced delays and difficulties.
- Technological limitations combined with time restrictions to prevent the design and use of a multi-lingual online version of this survey, which would have facilitated far greater reach (but still could have been supplemented with a paper version for those without internet access).
Annex 1 – Background of ITPC

The International Treatment Preparedness Coalition (ITPC) is a worldwide coalition of people living with HIV and their supporters and advocates. Its overall goals and strategies are signalled in its mission statement: Using a community-driven approach to achieve universal access to treatment, prevention, and all health care services for people living with HIV and those at-risk.

As of the end of 2008, thousands of individuals in 125 countries were directly affiliated with ITPC and working to achieve these goals at the local, regional and international levels. ITPC projects and initiatives include independent monitoring and advocacy reports; support for community-based advocacy and education; and expanding awareness and knowledge among community leaders in resource-limited countries on a range of scientific issues related to HIV/AIDS, including drug development and clinical research.

A significant percentage of ITPC’s work is conducted through a series of 11 regional networks. This structure ensures that priority is placed on identifying and responding to the needs of individuals living and working in communities where HIV is a direct, daily reality, not an abstract public health issue. ITPC’s regional governance structures ensure that people living with HIV are directly involved in all project development and implementation.
Annex 2 – Advisory Groups and Project Implementation Team

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Regional Coordinators
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BIZIYAREMYE BUKIKI Sylvère – West Africa Treatment Action Group (Cote d’Ivoire)
Rose Kaberia – East African Treatment Action Movement (Kenya)
James Kayo – Central African Treatment Access Group (Cameroon)
Shiba – Asia-Pacific Network of Positive People [APN+] (Thailand)
Alma de Leon – CIAT (Guatemala)
Patricia Figueroa – Caribbean Treatment Access Group (Puerto Rico)
Annex 3 – Survey Questions

1) For all respondents:
   - Age _____
   - Sex   _____Male    ____Female    ____Other
   - Country of residence ______________________
   - Location of residence _____urban    ____rural    _____somewhere in-between
   - Education level ____primary school    ___ high school _____university/post-univ

2) If HIV-positive:
   - Year diagnosed with HIV ______
   - Year began ARV treatment ______
   - ARV regimen ____________  +  ____________  + __ ___________  (+ ____________)
   - Where do you seek treatment?  ____hospital _____ health clinic    _____ NGO/charity  ____other
   - How do you pay for treatment? __________________________
   - Where are you currently living?  ______at home with family or partner   _____alone
   - ________ with friends   _____at charity or shelter _____other

3) What are the two most important reasons for you to seek ARV therapy? [please choose two most important reasons]
   - To stay alive
   - To improve my health or quality of life (or both)
   - To reduce burden on family
   - Because your doctor/friends/family said you had to get treatment
   - To regain social standing in the community
   - Because it was free and you had nothing to lose
   - Other (please explain:________________________________________________________
   - Other (please explain:___________________________________________________________________________

4) What are the three hardest things about taking ARVs?
   - side effects
   - requires strict adherence
   - number of pills/day
   - drug interactions (side-effects from taking many different drugs at the same time)
   - restrictions (food, drug times, etc)
   - understanding your doctor’s instructions
   - interference with traditional medicine or practices
   - fear that ARVs will not be effective and you will suffer even more
   - fear of drug stock-outs
   - not enough support from health workers
   - not enough support from friends, family, peers
   - paying for your medication or related costs (such as transportation to and from the hospital)
   - interference with religion or other social customs
   - fear of being publicly exposed as HIV-positive
   - fear that seeking treatment will create chaos in your life (job, family, etc)
   - Other (please explain:________________________________________________________
   - Other (please explain:___________________________________________________________________________

5) How serious do you consider the following issues:
   (please rank from 1-5, with 1=not serious and 5=very serious. If you don’t know or are not sure, please write “0”)
1. starting ARVs too early  
2. starting ARVs too late  
3. not having access to routine screening for OIs  
4. not having access to routine screening for side-effects  
5. not having access to superior or newer ARV combinations (eg TDF, Kaletra, T20)  
6. not having access to routine Viral Load testing  
7. not having access to routine CD4 testing  
8. not having peer counseling available in the clinic/hospital where you receive your meds  
9. not being sure you have a stable supply of ARVs  
10. not being sure how many months of ARVs you can afford to buy (if you must pay for them)  
11. not having full confidence in your doctor’s ability/knowledge but having no choice of doctors  
12. not being sure if your identity will be kept confidential at the treatment centre  
13. not having proper nutrition  
14. not having people to help you with adherence to ARVs  

6) If you are on ARVs, did you feel sick or have strong side-effects to any of the medicines you are taking?  
[Y/N]  
If No, please skip to the next question.  
If Yes…  
did you stop your medication? [Y/N]  
did you switch medications? [Y/N]  
If you did not stop or switch medications, please explain why not.  

7) What sorts of side-effects or other reactions to ARVs you think you could tolerate?  
☐ Mild rash  
☐ Severe rash  
☐ General physical discomfort or pain  
☐ Severe physical discomfort or pain  
☐ Fatigue  
☐ Mild nausea, vomiting or diarrhea  
☐ Severe nausea, vomiting or diarrhea  
☐ Difficult to sleep  
☐ Impossible to sleep  
☐ Nightmares  
☐ Numbness in fingers (or arms), toes (or legs)  
☐ Other (please describe)  

8) What sorts of side-effects or sickness would cause you to switch meds or stop treatment?  
☐ Mild rash  
☐ Severe rash  
☐ General physical discomfort or pain  
☐ Severe physical discomfort or pain  
☐ Fatigue  
☐ Mild nausea, vomiting or diarrhea  
☐ Severe nausea, vomiting or diarrhea  
☐ Difficult to sleep  
☐ Impossible to sleep  
☐ Nightmares  
☐ Numbness in fingers (or arms), toes (or legs)  
☐ Change in body shape/fat distributions (on face)  
☐ Change in body shape/fat distribution (other than face)  
☐ Other (please describe)
9) Do you think it’s better to start ARVs early even though there is the risk of side effects? [Y/N]
If Yes, what would you worry about starting ARVs early?
_____________________________________________________________________________
_____________________________________________________________________________
10) If you are on ARVs, have you ever interrupted your treatment for more than one day?
☐ No (skip to next question)
☐ Yes
If so, why?
☐ your own choice
☐ doctor’s advice
☐ some other external factors? (please explain _____________________________)
If so, how long did you stop treatment?
☐ less than 1 week
☐ more than 1 week but less than 1 month
☐ more than 1 month
If so, why did you stop treatment?
_____________________________________________________________________________
11) How serious a problem do you think it is if you stop your ARVs for many days or weeks?
☐ extremely serious
☐ moderately serious
☐ not very serious
☐ not serious at all
☐ don’t know
12) Is the topic of ARV drug resistance discussed and the risk of drug resistance well understood by PLHIV in your country/community?
☐ well understood
☐ moderately understood
☐ little understood
☐ not understood at all
☐ not discussed or mentioned
☐ don’t know
13) Is ARV drug resistance testing available in your country or community?
☐ available
☐ not available
☐ don’t know
14) Is ARV drug resistance testing available where you receive treatment?
☐ always available for all PLHIV on ART
☐ sometimes available for PLHIV on ART
☐ rarely available for PLHIV on ART
☐ never available for PLHIV on ART
☐ don’t know
15) Is ARV drug resistance testing accessible and affordable (or free) for all those who need it in your community?
☐ yes
☐ no
☐ don’t know
If no, why not? ________________________
16) Is TB testing routinely offered to all PLHIV in your country/community as part of a standard package of care and treatment?
☐ yes
17) Is TB treatment routinely available for PLHIV in your country/community?
- [ ] yes
- [ ] no
- [ ] don’t know
  If yes, is there a charge for TB treatment?

18) Are there any entry restrictions for TB treatment in your country/community?
- [ ] Yes (please explain _______________________________________________________________)
- [ ] No
- [ ] Don’t know

19) What drugs are used for 1st line TB treatment?

20) Are there any recent problems with stock-outs of these drugs?
- [ ] Yes (please explain _______________________________________________________________)
- [ ] No
- [ ] Don’t know

21) Is it common for PLHIV to have problems starting and/or continuing TB treatment if they are already on ARVs?
- [ ] Very common*
- [ ] A little common*
- [ ] Not common at all*
- [ ] Rare
- [ ] Don’t know
  If it is common, please explain.

22) Is there an alternate (2nd line) TB treatment regimen available? [Y/N]
  - If 2nd line is available, is it free? [Y/N]
  - If not free, is it too expensive for most people to afford? [Y/N]
  - If 2nd line is available, what are the procedures to start? What if people appear to be failing clinically? Is DST available? How long does it take to get?

23) Is TB treatment education and information provided to all PLHIV within treatment/prevention programmes? [Y/N]

24) Is Resistant TB a problem among PLHIV?
  If so, what is being done about it?
- [ ] Nothing or very little
- [ ] Prevention, early detection and treatment education
- [ ] Treatment for those with resistant TB
- [ ] don’t know

25) (For those on ARVs) Were you confused about how to take both ARVs and TB treatment? [Y/N]
  If Yes, please describe __________________________________________________________

26) (For those on ARVs) Did you have complications or problems when you started ARVs due to TB treatment? If Yes, please describe __________________________________________________________

27) Is treatment available for Hep-B? [Y/N]
If available, is it at primary health care level? [Y/N]
If yes, is it free? [Y/N]
If not free, is it expensive and hard to pay for? [Y/N]

28) Is treatment available for Hep-C [No/Yes]
   If available, is it at primary health care level? [Y/N]
   If available, is it free? [Y/N]
   If not free, is it hard to afford (expensive)? [Y/N]

29) Are all PLHIV given information about Hep-B and Hep-C?
   □ Yes, all the time*
   □ Yes, sometimes*
   □ Rarely
   □ No, never
   □ don’t know
   □ If yes, is the information given as part of routine treatment education programmes [Y/N]
   □ If information about Hepatitis is not given to all PLHIV, are only some PLHIV given this information?
   □ If so, which ones? _________________________

30) Among PLHIV in your community, how well understood is the issue of Hepatitis/HIV co-infection?
   □ well understood
   □ moderately understood
   □ little understood
   □ not understood
   □ not discussed or mentioned
   □ don’t know