

## Consultation Report

# Community Consultation

to inform the 2013 WHO Consolidated ARV Guidelines on the Use of Antiretroviral Drugs  
for Treating and Preventing HIV Infection



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Designed by Progression  
September 2013

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## Abbreviations

### 2013 ARV Guidelines

3TC  
ABC  
ART  
ARV  
AZT  
d4T  
EF  
EFV  
ES  
FTC  
GNP+  
HTC  
LPV/r  
MSM  
NNRTI  
NVP  
Option B+  
PLHIV  
PrEP  
PMTCT  
SRH  
TasP  
TDF  
WHO  
WLHIV

### 2013 WHO Consolidated ARV Guidelines on the Use of Antiretroviral Drugs for Treating and Preventing HIV Infection

Lamivudine  
Abacavir  
Antiretroviral therapy  
Antiretroviral drugs  
Zidovudine  
Stavudine  
E-forum  
Efavirenz  
E-survey  
Emtricitabine  
Global Network of People Living with HIV  
HIV testing and counselling  
Lopinavir /ritonavir  
Men who have sex with men  
Non-nucleoside reverse transcriptase inhibitor  
Nevirapine  
Lifelong ART for Pregnant Women  
People living with HIV  
Pre-exposure prophylaxis  
Prevention of mother-to-child transmission  
Sexual and reproductive health  
Treatment as prevention  
Tenofovir  
World Health Organization  
Women living with HIV



# Executive summary

Expanding antiretroviral therapy (ART) access is a cornerstone of reducing mortality and improving health outcomes among people living with HIV (PLHIV) in all settings. Given recent advances in scientific evidence on the use of antiretroviral drugs (ARVs) for HIV treatment, including their impact on health outcomes and HIV prevention, the World Health Organization (WHO) has reviewed and consolidated all ARV-related guidelines into a single compendium for publication in 2013. The 2013 **WHO Consolidated ARV Guidelines on the Use of Antiretroviral Drugs for Treating and Preventing HIV Infection** (2013 ARV Guidelines) focus on four areas: (1) clinical guidelines for adults and adolescents; (2) clinical guidelines for maternal and child health; (3) operations and service delivery guidance (for the first time); and (4) guidance for programme managers.

Recognising the importance of the full involvement of people living with HIV and other key populations<sup>1</sup> in planning, implementing and evaluating high-quality, rights-based HIV care and treatment programmes, the International HIV/AIDS Alliance (the Alliance) and the Global Network of People Living with HIV (GNP+) conducted a series of community consultations to establish values, preferences, concerns and recommendations related to a number of priority areas for the 2013 ARV Guidelines.

The community consultations utilised the following methods: an e-survey, e-forum discussions and thematic focus group discussions. The multi-language online e-survey explored key preferences regarding ART initiation and operational aspects of ART service delivery for different populations. Moderated multi-language e-forum discussions explored more nuanced or contentious aspects of the same topics. Additionally, GNP+ and the International Community of Women Living with HIV (ICW) conducted focus group discussions in Uganda and Malawi, exploring perspectives on and experiences of lifelong ART for pregnant women living with HIV (WLHIV) (Option B+) to protect the health of women and prevent mother-to-child transmission of HIV.

Conducted between November 2012 and January 2013, these community consultations provided some key considerations for particular 2013 ARV Guidelines recommendations and for country-level implementation. The findings are subject to some limitations, including use of Internet-based methodology that resulted in a non-randomised sample of e-survey and e-forum respondents. However, the focus group discussions provided in-depth insight for recommendations related to pregnant women and prevention of mother-to-child transmission (PMTCT), thereby strengthening the findings of the consultation.

Overall, 1,088 people from 117 countries responded to the e-survey; 955 people subscribed to the e-forums and posted 155 responses; and 88 people participated in the focus group discussions in Uganda and Malawi. The surveyed populations included people living with HIV, people not living with HIV, transgender people, pregnant women, adolescents and other young people, men who have sex with men (MSM), people who inject drugs, sex workers, refugees and migrants. Both the e-forum and the e-surveys included respondents from Africa, Middle East, Asia, North America, Caribbean, Latin America, Eastern and Western Europe, and the Pacific regions. The focus group discussions in Uganda and Malawi included both men and women.

## Main findings and recommendations from community respondents

### ART for adults and adolescents<sup>2</sup>

- **When to start treatment among adults:** the majority of those respondents living with HIV supported early ART initiation at CD4 of 350–500 cells/mm<sup>3</sup> using newer, more effective, less toxic and safer regimens.
- **What to start:** many of those taking stavudine (d4T) did not wish to continue with it.
- **Adopting a rights-based approach in ART provision:** respondents emphasised that while access to treatment can benefit individuals and their sexual partners, treatment programmes must adopt a rights-based approach and must not result in key populations being forced to test, accept treatment against their wish or undergo unwanted procedures (e.g. forced sterilisation).
- **Use of treatment in combination with other prevention interventions:** Respondents were of the view that treatment (including its use for prevention) should be paired with, and not replace, behavioural, structural and other prevention interventions. This is essential to ensure that treatment, care and support packages comprehensively meet the clinical, psychosocial and other related needs of people living with HIV, their sexual partners and family members.

1. This term describes populations disproportionately impacted by HIV. While key population groups defined for a particular setting will depend on the epidemic and social dynamics, they principally include gay men and other MSM, women and men who inject drugs, sex workers and transgender people. Source: UNAIDS (2011), Guidance for partnerships with civil society, including people living with HIV and key populations.

2. WHO defines “adolescents” as individuals aged 10 to 19 years.

## ART for pregnant women and the prevention of mother-to-child transmission of HIV

- **Option B+:** most community respondents, including women living with HIV, supported offering lifelong ART during pregnancy. However, they noted that guaranteed access to ART and regular monitoring are critical factors determining the success of Option B+ in many countries.
- **Service quality and capacity:** respondents also identified an imperative to address service quality and capacity constraints. This includes ensuring that linkages between sexual and reproductive health (SRH) and HIV services are strengthened; investing in approaches that increase retention of mothers and children in care; and building the capacity of communities to deliver PMTCT interventions through a sustainable task-shifting strategy.
- **Potential inequity issues:** respondents identified potential inequity of ART access between pregnant and non-pregnant women living with HIV as another concern to be addressed.
- **Option B+ and structural interventions:** community respondents affirmed that countries ought to prioritise addressing social, legal and ethical impediments to Option B+ (including stigma and discrimination, gender-based violence, criminalisation of HIV exposure, and forced sterilisation).

## ART for children

- **When to start ART among children:** nearly half of the respondents were of the opinion that children should initiate ART immediately after a positive HIV diagnosis.
- **What to start:** for children younger than three years old, and despite the known difficulties of storing and administering lopinavir/ritonavir (LPV/r) syrup, respondents still preferred regimens with greater effectiveness. For children over three years old, respondents preferred tenofovir-lamivudine Efavirenz (TDF-3TC-EFV) as a first-line regimen.
- **Considering local context and resources:** respondents highlighted the need to consider the contexts within which ART will be delivered for paediatric and other populations. They highlighted current barriers to paediatric treatment, to include lack of refrigeration, stigmatising attitudes and a lack of psychosocial support.

## The use of ART for prevention in HIV- negative people

- **Sero-discordant couples:** respondents supported initiating ART for sero-discordant couples regardless of CD4 cell count. However, they reiterated that treatment as prevention (TasP) should be implemented as part of a combination approach, which includes behavioural, biomedical and structural interventions, and that ensures that potential human rights violations, coercion, and stigma and discrimination experienced by people living with HIV and other key populations are mitigated.

## Use of ART for prevention

- **Pre-exposure prophylaxis:** respondents expressed widespread support for key populations to access pre-exposure prophylaxis (PrEP), including women or men who are not in a position to negotiate safer sex, MSM and women or men who are potential victims of gender-based violence, among others.<sup>3</sup> However, respondents reiterated that known barriers related to cost, stigma and discrimination, and side effects must be addressed for PrEP to be effective.

## Operational recommendations

- Respondents widely supported task-shifting/sharing from doctors to nurses and from nurses to community health workers. They identified important barriers to task-shifting/sharing, to include current policies and regulations that do not enable task-shifting/sharing, as well as poor remuneration of community health workers, all of which must be addressed.
- Community respondents supported integrating ART into other health services, and vice versa, as an essential strategy to increase access.
- Respondents supported decentralisation of services in order to bring services closer to the community. They reiterated that decentralisation will reduce barriers associated with travelling long distances to access centralised services. However, they pointed out that service integration and decentralisation must be implemented in a sensitive manner so that services remain available and acceptable to communities (particularly key populations), without exacerbating stigma and discrimination.

## Programmatic recommendations

- Community respondents supported a public health approach of ensuring that the largest numbers of people possible have access to HIV-related services, including ART access. However, respondents also felt that ethical and fair approaches that uphold respect for human rights and personal choice are equally important to safeguard the overall wellbeing of people living with HIV.
- In that respect, community respondents raised many important human rights and ethical considerations for implementing the 2013 ARV Guidelines. While new approaches, such as early initiation of ART, are valuable, respondents were of the view that that a clear

3. Community responses regarding key populations do not necessarily reflect the views of key populations themselves.

understanding of and commitment to the protection of human rights must accompany such new interventions. They reiterated that rights assessments and monitoring should be used to safeguard individual rights, ethical standards, confidentiality and personal choice. In addition, respondents were of the view that laws that criminalise HIV exposure, transmission, non-disclosure and behaviours of key populations should be mitigated and repealed.

- Additionally, community respondents highlighted that implementation of the 2013 ARV Guidelines should address social and structural barriers, including stigma, gender-based violence, gender inequity, homophobia, poverty and food security.
- Finally, community respondents emphasised the need to meaningfully engage communities in planning, implementing and evaluating ART programmes through local- and country-level structures (e.g. community advisory boards and national coordinating bodies). They emphasised that while community-level services are essential, they should not be seen as a cost-saving measure. Rather, community respondents noted that engaging communities should go hand in hand with community systems strengthening, as well as improving linkages between community-level interventions and health systems.

In summary, while this consultation informed the development of the 2013 ARV Guidelines, community respondents are calling for continued and strengthened community involvement at all levels once countries begin adapting and implementing the guidelines.

# Introduction

ART is a preventive and therapeutic cornerstone of comprehensive efforts to reduce transmission, morbidity and mortality linked to HIV. In view of recent advances in scientific evidence on the use of ARVs for HIV treatment and prevention, WHO is reviewing and consolidating all of the WHO ARV-related guidelines into a single compendium for publication in 2013. The 2013 ARV Guidelines focus on four areas: (1) clinical guidelines for adults and adolescents; (2) clinical guidelines for maternal and child health; (3) operations and service delivery guidance (for the first time); and (4) guidance for programme managers.

Input from all stakeholders is needed in order to make these guidelines comprehensive and supportive of countries and communities of people living with HIV and other key populations in achieving key global targets on HIV prevention, treatment, care and support.<sup>4</sup> Particularly with the advent of additional TasP approaches, the full involvement of people living with HIV and key populations in planning, implementing and evaluating high-quality, rights-based HIV prevention, care and treatment programmes is required for the next phase of HIV treatment, as noted in the UNAIDS 2012 report on the global AIDS epidemic<sup>5</sup> and the 2011 WHO treatment 2.0 framework.<sup>6</sup> WHO has therefore supported a series of consultations so that the experiences, preferences and values of communities, particularly people living with HIV and other key populations, can inform the content and implementation process of the 2013 ARV Guidelines.

## Box 1. Terminology

**Key populations:** This term refers to groups of people who are vulnerable to or affected by HIV and whose involvement is vital to an effective response. The groups vary according to the local context, but are often marginalised or stigmatised because of their HIV status, gender, sexual orientation or social identities. In all settings, key populations include people living with HIV. In most settings, they also include people who sell or buy sex, MSM, transgender people, people who inject drugs, sero-negative partners in sero-discordant couples, and children affected by HIV. They may also include partners and families of people living with HIV, migrants, displaced people and prisoners, among others. Gender inequalities and harmful gender norms may also increase women's vulnerabilities to HIV. Each country will define the specific populations that are key to their epidemic and response based on the epidemiological and social context.<sup>7</sup>

**Community:** This term has no single or fixed definition. Rather, it consists of people who are connected to each other in distinct and varied ways. Community members may live in the same area or they may be connected by shared experiences, challenges, interests, living situations, culture, religion, identity or values. Communities are diverse and dynamic, and a person may belong to more than one community.

**Civil society:** This term encompasses the wide range of organisations and bodies that are not under direct government control and have a range of useful functions in support of a country's citizens. Civil society includes community-based organisations or networks, non-governmental organisations or networks, private sector bodies and businesses. They can act as advocates and critics of government, mobilising communities and helping to shape policy. They provide health, social or economic support and services that complement, are alternatives to, or fill gaps in government provision.

**Treatment as prevention:** In this community consultation, this term refers to the offer of ART to people living with HIV to decrease the chance of HIV transmission, regardless of their CD4 cell count.

## Rationale and aims of the consultation

In recognition of the critical role of communities and civil society, in particular people living with HIV and other key populations, the Alliance and GNP+ conducted a community consultation to establish values, preferences, concerns and specific recommendations related to a number of priority areas for the 2013 ARV Guidelines. GNP+ and ICW also conducted focus group discussions in Uganda and Malawi on using Option B+ to prevent mother-to-child transmission and protect the health of those women and their partners.

The consultations took place in November and December 2012, supported by an ad hoc Community Consultation Working Group that included members of the WHO Civil Society Reference Group and community representatives to the WHO Guideline Development Groups.

The agreed aims of the consultation were:

1. To solicit maximum input and feedback from civil society and communities most affected by HIV (i.e. key populations, including people living with HIV) on the agreed key topic areas.

4. UNAIDS. 2011 Political declaration: targets and elimination commitments. Available at: <http://www.unaids.org/en/targetsandcommitments/>

5. UNAIDS (2012), Global report: UNAIDS report on the global AIDS epidemic 2012. Available at: [http://www.unaids.org/en/media/unaids/contentassets/documents/epidemiology/2012/gr2012/20121120\\_UNAIDS\\_Global\\_Report\\_2012\\_with\\_annexes\\_en.pdf](http://www.unaids.org/en/media/unaids/contentassets/documents/epidemiology/2012/gr2012/20121120_UNAIDS_Global_Report_2012_with_annexes_en.pdf)

6. WHO (2011), The treatment 2.0 framework for action: catalysing the next phase of treatment, care and support. Available at: <http://www.who.int/hiv/pub/arv/treatment/en/index.html>

7. UNAIDS (2011), UNAIDS terminology guidelines (October 2011). Available at: [http://www.unaids.org/en/media/unaids/contentassets/documents/unaidspublication/2011/JC2118\\_terminology-guidelines\\_en.pdf](http://www.unaids.org/en/media/unaids/contentassets/documents/unaidspublication/2011/JC2118_terminology-guidelines_en.pdf) (accessed 10 June 2013).

8. The full e-survey can be found in Annex 1.



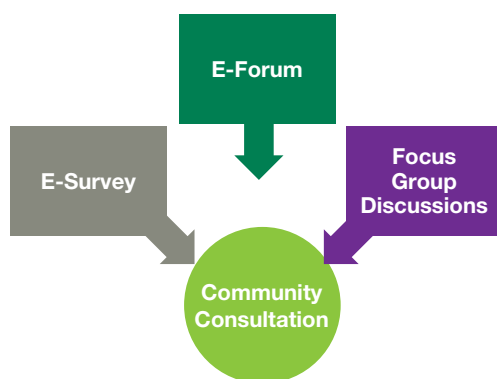
2. To enable dialogue and encourage positive contributions towards improving the content, substance and usefulness of the 2013 ARV Guidelines, and to ensure that they meet the needs and requirements of civil society and communities most affected by HIV.
3. To sensitise communities and civil society regarding how they can engage throughout the development process of the 2013 ARV Guidelines.

## Methodology

### What was done?

The consultation was conducted using the following three methods:

1. An online e-survey,<sup>8</sup> using SurveyMonkey®, explored key preferences in relation to what ART to provide and when to provide it to different populations, and some of the service delivery and operational considerations for ART delivery for adults, pregnant and post-natal women, and children. Questions were developed based on the topics that WHO investigated through PICO questions,<sup>9</sup> and expanded on based on issues of particular importance to communities and civil society. Questions were reviewed and revised by the Community Consultation Working Group. All questions were optional (i.e. could be left blank), with the exception of questions regarding consent to participate and age.
2. Moderated e-forum discussions explored more complex, nuanced or contentious aspects of the consultation topics. A one-week period was allocated to each of the four main topics.
3. Focus group discussions in Malawi and Uganda explored the perspectives and experiences of women and their partners living with or affected by HIV regarding the use of Option B+ to prevent mother-to-child transmission of HIV.



### Which languages were used for the consultation?

The e-survey was conducted in six languages: English, French, Spanish, Russian, Arabic and Chinese. The e-forums were conducted in five languages: English, French, Spanish, Russian and Arabic. The focus group discussions in Malawi were conducted in Chichewa, with simultaneous translation into English; those in Uganda were mainly conducted in English with translation into Luganda as needed.

### How were people living with HIV and other key population communities informed of the consultation?

Information about the consultation (invitations to complete the e-survey and subscribe to the e-forums) was shared through the GNP+ website, GNP+ Facebook pages, and national and regional networks of people living with HIV and other key populations. Information was circulated by the Alliance through their website and intranet, with a request to share as widely as possible with non-governmental organisations, community-based organisations and community-level contacts. WHO HIV/AIDS Department also circulated information through its networks. Further messages were posted on a wide range of global, regional and national list servers used by communities of people living with HIV, non-governmental organisations and community-based organisations concerned with HIV care and treatment (e.g. AIDSPortal website, British Medical Journal blog pages). All e-survey respondents and e-forum subscribers will have access to the final report and annexes. Focus group discussion participants were recruited by national network of women living with HIV.

### How were the e-survey, e-forums and focus group discussion results analysed?

E-survey responses were analysed using SPSS® (IBM) and Excel® (Microsoft). A variety of statistical tests were performed to investigate significant differences in responses. Due to the structure of questions and options, weighting/ranks were assigned to given responses and used to calculate overall ratings of importance/agreement for each option.<sup>10</sup> A higher rating indicated that more respondents agreed with a statement or felt an option was more important.

9. PICO is a method of putting together a research strategy that employs a more evidence-based approach to literature review. PICO stands for (1) Patient/Population (Who or what?); (2) Intervention (How?); (3) Comparison (What is the main alternative – if appropriate?); and (4) Outcome (What are you trying to accomplish, measure, improve, effect?).

10. Respondents had the option to skip questions. Thus the total number of respondents varied across questions.

E-survey responses were also sub-analysed according to the respondents' demographics. In many cases, the number of respondents who identified with most key populations was very small and did not affect the overall answer to the question. The exception was MSM, who represented 21% of survey respondents. This percentage was even higher for most of the questions, since MSM who participated in this survey were more likely to respond to survey questions (rather than skipping them) compared to other population groups. Consequently, attention should be paid to those questions and responses showing statistical differences for MSM.

E-forum content was analysed by identifying common themes and areas of strongest consensus in each discussion. Additionally, specific operational, rights, ethics and community-focused implications and recommendations from each discussion were also identified and summarised through a narrative.

Standard qualitative thematic analysis was applied to the focus group discussion transcripts.<sup>11</sup>

## Limitations

The consultation was subject to a number of limitations that should be noted when interpreting the findings:

1. Specific topics were selected for the community consultation from the full set of topics covered by the 2013 ARV Guidelines. Some topics were expanded on to address gaps in knowledge on community perceptions and preferences. Other topics that addressed highly technical issues were omitted on the grounds that responses were only likely to be received from people with very high levels of technical knowledge.
2. The e-forum and e-survey responses came only from respondents who had access to the Internet. Therefore, the data cannot be used to represent the opinions of broader groups of people living with HIV, other key populations or communities as a whole.
3. The length of the survey and its attempt to address so many aspects of the guidelines meant that some respondents who started the survey may not have answered all the questions.
4. The technical nature of some of the consultation topics and questions may have affected overall participation, particularly in responding to e-forum questions and in settings where access to technical information by people living with HIV and communities is currently limited.
5. E-forum responses during week four were limited, possibly due to proximity to the December holiday period. A number of related consultations and studies were running during the same period, and this may have limited responses from some groups (e.g. sex workers and transgender people) and from some regions (particularly Latin America).
6. In-depth statistical analysis of e-survey responses have been limited by a number of factors:

### Datasets

- Respondents were permitted to skip questions and only small subsets of respondents answered some of the questions. For reference, the total numbers of respondents is noted for each question throughout the report.
- Only small numbers of respondents self-identified as members of specific population groups (e.g. adolescents, over-65 year-olds, transgender people), yielding results that did not have sufficient sample sizes for reliable and accurate statistical interpretation. For reference, the total numbers of respondents self-identifying with specific populations is noted for each question throughout the report.
- Incorrect data entry by some respondents invalidated some answers (e.g. respondent identifying as both "male" and "pregnant woman").

### Question structure

- For many questions with multiple options, almost all options were deemed to be "important". Weightings needed to be assigned by the analyst rather than allowing respondents to rank the importance or limit the number of options deemed "important".
- The wording of some questions resulted in ambiguous answers that are difficult to interpret with certainty. No data or analysis is therefore offered for these questions in this report.
- The structure of questions differed, in terms of the range of options possible selections. The ratings calculated for one question are not comparable to the ratings of another question if the question structures are not the same.

### Discerning between opinion, bias and knowledge

- For some questions regarding services provided to key populations, answers may have been biased by respondents' opinion of the service rather than their opinion about a key population. Alternatively, for some questions regarding barriers to services, answers may have been biased by respondents' opinion about a key population rather than access issues.

11. For the full analysis of the focus group discussion data, see <http://www.gnpplus.net/>

# Who responded to the consultation?

## E-survey

Overall, 1,088 people from 117 countries responded to the e-survey. The following tables show numbers of respondents with particular attributes. Note: all questions were optional (with the exception of consent to participate and age).

E-survey respondents							
Gender (of those who identified their gender; n=791)							
Male		Female			Transgender		
484 (61.2%)		298 (37.7%)			9 (1.1%)		
HIV status (of those who disclosed their HIV status; n=864)							
People living with HIV		HIV negative people			Don't know		
431 (49.9%)		406 (47%)			27 (3.1%)		
Key populations (of those who self-identified; n=489)							
Pregnant women <sup>12</sup>	Young people 20–24	Adolescents 10–19	MSM	Trans-gender	People who injects drugs	Sex workers	Refugees/ migrants
80 (16.4%)	61 (12.5%)	14 (2.8%)	220 (45%)	14 (2.8%)	28 (5.8%)	30 (6.1%)	42 (8.6%)
Age (of those who disclosed their age; n=880)							
10–19	20–24	25–34	35–44	45–54	55–64	65+	
10 (1.1%)	53 (6.1%)	264 (30%)	280 (31.8%)	189 (21.5%)	67 (7.6%)	17 (1.9%)	
Country income status <sup>13</sup> (of those who responded to the question on income status; n=831)							
Low		Middle			High		
174 (20.9%)		489 (58.9%)			168 (20.2%)		

Note: Sub-analysis of responses by epidemic type as defined by WHO in respondents' countries of residence was carried out but did not yield statistically useful data, so has been omitted.

## E-forums

There were 955 subscribers to the e-forums overall, distributed across languages as shown.

Focus group discussion participants		
E-forum	Total # subscribers	# Responses
ARV English	546	68
ARV French	99	34
ARV Russian	68	20
ARV Spanish	74	19
ARV Arabic	168	14
Total	955	155

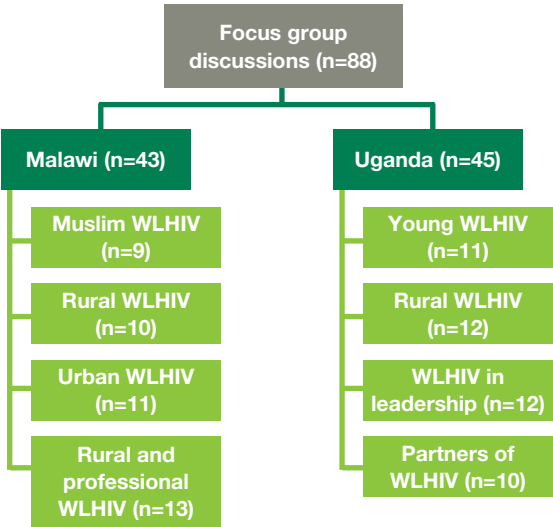
No demographic details were requested from subscribers. Some of the contributors indicated their current country of residence. A total of 155 responses were received throughout the four-week duration of each e-forum.

12. A woman who is pregnant or has been pregnant in the last two years, or is planning to have a child in the next two years.

13. World Bank "Country Income Status" definitions were used.

Focus group discussions

A total of 88 people participated in eight focus groups (four in each country). In Uganda there were 35 female and 10 male participants, with an average age of 36 years (range 17–56). In Malawi there were 43 female participants, with an average age of 31 years (range 20–44).



## Key findings

This section provides a summary of findings, incorporating those from the December 2012 multi-language e-survey and e-forums, and from the November 2012 focus group discussions in Malawi and Uganda regarding Option B+ to prevent mother-to-child transmission of HIV.<sup>14</sup> Reference is also made to findings from the Treatment 2.0 consultation meetings held in Harare<sup>15</sup> and Bangkok<sup>16</sup> during March and September 2013 respectively, as a way of triangulating our findings from other community consultations. The e-survey and e-forum questions are provided in Annexes 1 and 2.

This consultation was intended primarily to inform development of the 2013 ARV Guidelines. However, people living with HIV and other key populations may also find this report useful in their advocacy for prevention, care and support, rights-based service delivery, and linkages between community and health systems to optimise HIV treatment access and retention in care.

Accordingly, key considerations from the consultation on clinical approaches, programmatic issues and community engagement, as well as issues relating to rights, equity and ethics, are highlighted as appropriate in each section.<sup>17</sup>

## 1. Guiding principles for HIV care and ART programming

Throughout the consultation, community respondents highlighted several important guiding principles relevant for developing and implementing the 2013 ARV Guidelines. They are featured here to set the stage for the remaining consultation findings.

Consultation results showed that successful implementation of the 2013 ARV Guidelines requires:

- an enabling environment, where the human rights of key populations are protected and promoted, and stigma and discrimination are eliminated, not only in relation to HIV but also gender, social status, poverty and reproductive rights (see ES42, ES70 and programmatic EF discussions).
- developing and implementing service delivery strategies, innovations and models in partnership with people living with HIV and other key populations, so that successful approaches can be scaled up (see programmatic EF discussions).
- resourcing for community mobilisation, including support for core costs and capacity-building for community-based organisations and networks, and strengthening linkages between community and health systems (see programmatic EF discussions).
- task-shifting to nurses and community-based workers, with appropriate training, certification and remuneration for lay counsellors, HIV caregivers and other community health workers (see ES63, ES64 and ES67 discussions).
- integration within HIV service interventions to remove duplication, reduce the burden on patients, and deal with inefficiencies in testing, patient enrolment and community mobilisation (see ES28, ES68 and ES69 discussions).
- including gender strategies to address critical treatment barriers facing women and girls and to reduce their burden of care; also strategies to address high mortality and attrition rates among men because of late diagnosis, poor adherence to ART and very high rates of loss to follow-up (see ES29, ES39, ES49, ES50, ES51, ES53, and ES58 discussions).
- focusing on children and adolescents, by expanding access to HIV testing, care and treatment, and addressing specific issues, including stigma and human rights violations in healthcare settings related to these and other populations (see ES31-ES34 and maternal and child health EF discussions).

14. GNP+ (2013), Option B+: understanding perspectives/experiences of women living with HIV. Available at: <http://www.gnpplus.net/>

15. World Health Organization and the Pangaea Global AIDS Foundation. Draft meeting report on optimizing HIV treatment access and retention in care: linking community-level interventions with health care delivery systems in Sub-Saharan Africa, 26-28 March 2012. Available at: <http://hivtreatmentoptimization.org/events/optimizing-hiv-treatment-access-and-retention-care-linking-community-level-interventions-0> (accessed 11 June 2013).

16. Optimising HIV treatment access and retention in care: linking community level interventions with healthcare delivery systems. A Treatment 2.0 initiative organised by the Asian Pacific Network of People Living with HIV/AIDS and the Pangaea Global AIDS Foundation in Partnership with WHO and UNAIDS September 18 – 20, 2012 Bangkok, Thailand. Available at: <http://hivtreatmentoptimization.org/events/optimizing-hiv-treatment-access-retention-care-bangkok-thailand-15> (accessed 11 June 2013).

17. Note that data regarding key populations are collective views of the community respondents and may not necessarily reflect the views of the specific groups mentioned.



## 2. Clinical HIV care

### A. HIV testing and counselling

#### Key questions

1. What are the main barriers that must be addressed to improve HIV treatment access in your setting? (ES49, n=399)
2. Which groups have the greatest difficulty accessing HIV testing and counselling (HTC) in your context? (ES53, n=359)
3. The following approaches would increase access to HTC. Do you agree with these statements? (ES54, n=366)
4. The following factors are important advantages or disadvantages of community-based testing and counselling in your setting. Do you agree with these statements? (ES55, n=362)

#### Access to HIV testing and counselling

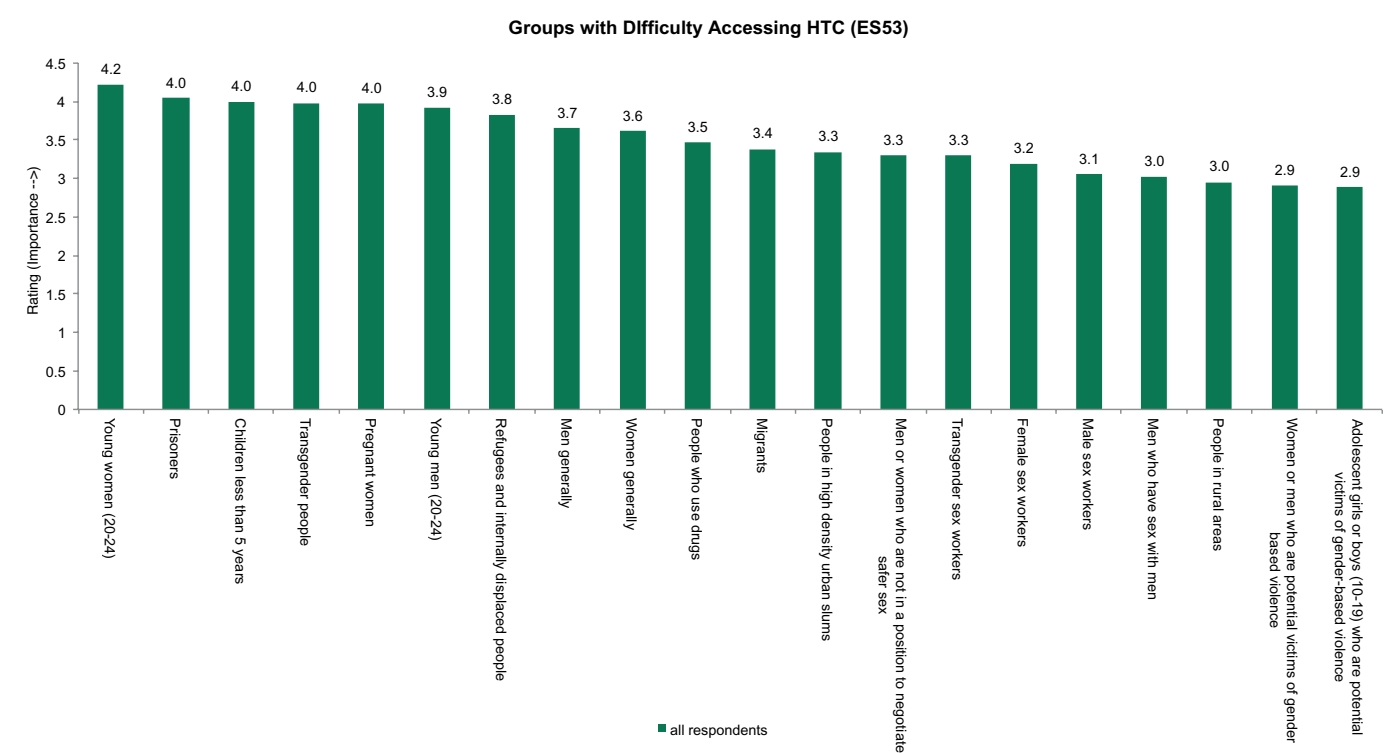


Figure 1. Groups with difficulty accessing HIV testing and counselling (n=359)

Community respondents highlighted a lack of access to HTC as an important barrier to accessing HIV treatment. Community respondents from low-income countries reported generally low levels of access across all specified groups.<sup>18</sup> Analysis by age group showed that people aged 20–24 years responded somewhat differently to older age groups, perceiving a greater difficulty for men generally and young men (aged 20–24) in particular in accessing HTC.

18. Community respondents chose from 20 different key population groups. Refer to Annex 1 for the list of options.

## Community-based testing

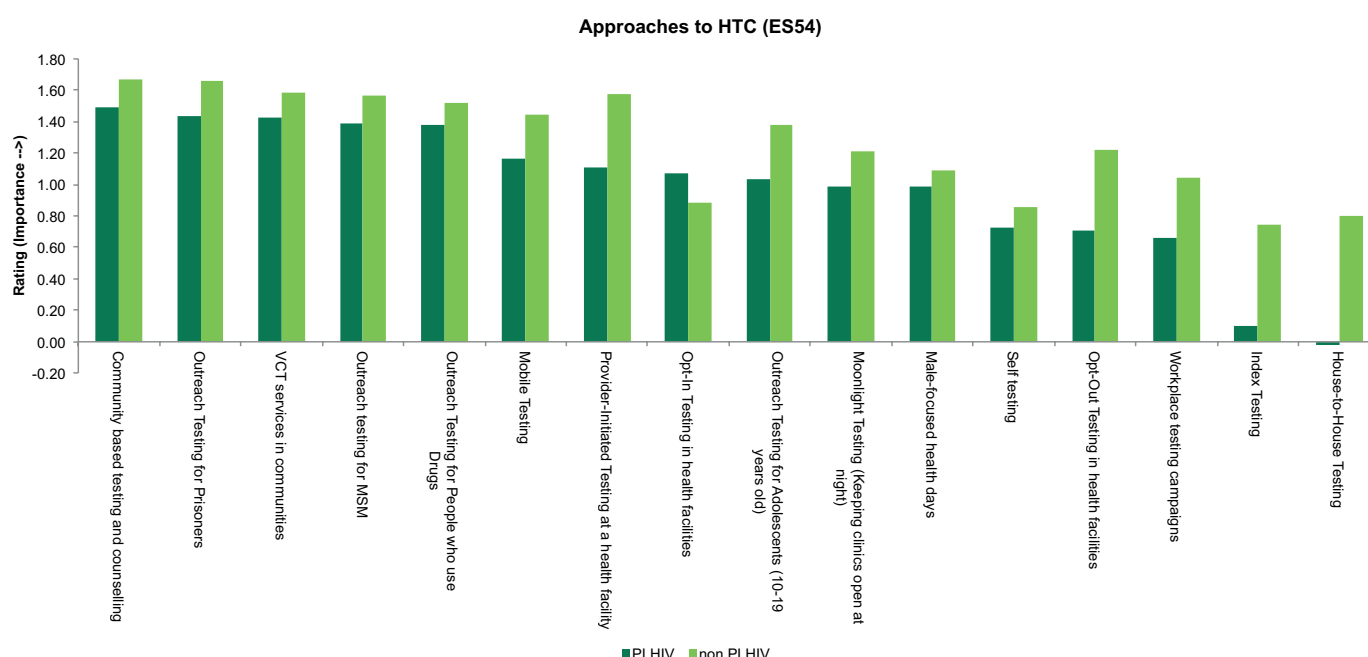


Figure 2. Approaches to HIV testing and counselling (n=366)<sup>19</sup>

Community respondents agreed that community-based testing and counselling, outreach testing to prisoners, and voluntary counselling and testing in communities would increase access to HTC. However, respondents living with HIV expressed different preferences compared to those not living with HIV. For instance, people living with HIV disagreed that house-to-house testing would increase access to HTC (-0.02), compared to those not living with HIV who marginally agreed (0.80). Respondents living with HIV had stronger preferences for opt-in testing in health facilities (1.07), while respondents not living with HIV preferred opt-out testing in health facilities (1.22). In general, respondents not living with HIV were more in favour of most of the other options of HTC. This illustrates, as do a number of responses to other e-survey questions, that there are often differences in perceptions between those living and those not living with HIV. Consultation with respondents about their experiences and preferences when planning HTC and other HIV-related services is therefore critical to programming and service delivery.

19. The range was from 2 (strongly agree) to -2 (strongly disagree).

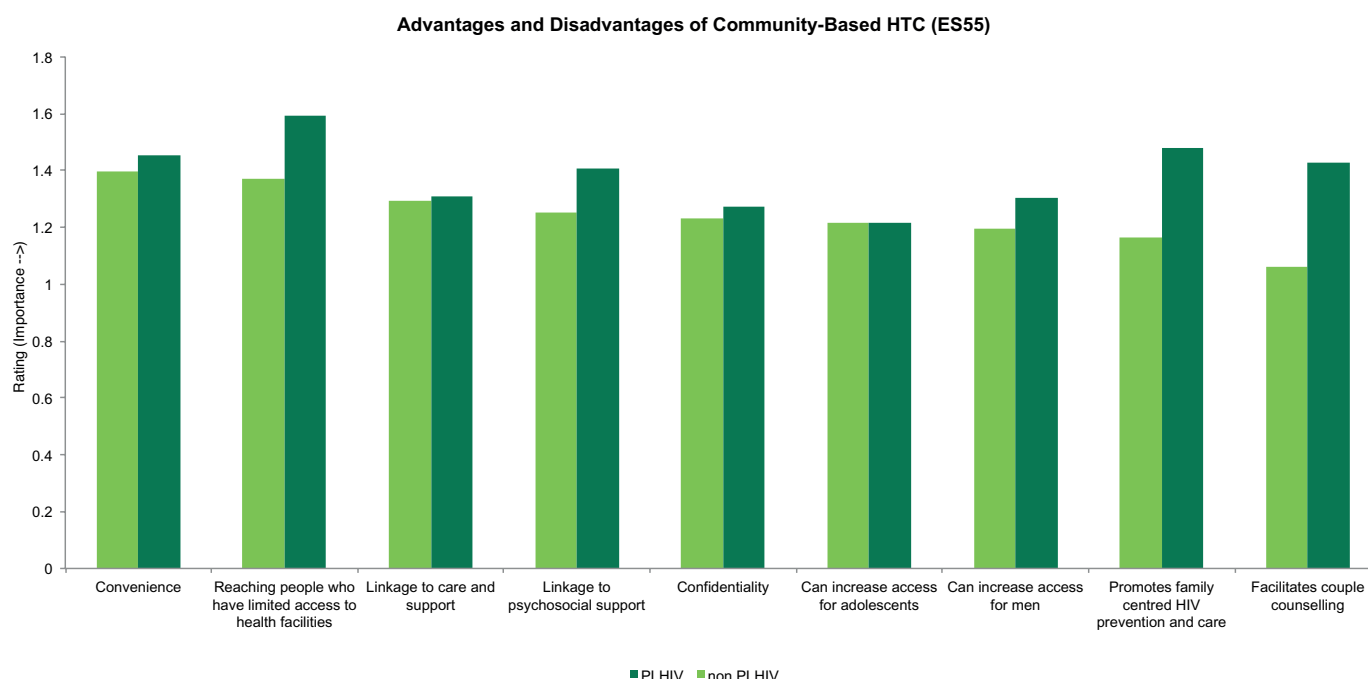


Figure 3. Advantages and disadvantages of community-based HIV testing and counselling (n=362)<sup>20</sup>

Respondents generally agreed that the main advantages of community-based testing include reaching people who have limited access to health facilities, convenience, linkage to psychosocial support, and linkage to care and support. However, there were some differences again between people living with HIV and those not living with HIV. The latter rated “facilitates couple counselling” (1.43) and “promotes family-centred HIV prevention and care” (1.48) as far greater advantages than did the former (1.06 and 1.16, respectively). Respondents from low-income countries strongly agreed that community-based testing “promotes family-centred HIV prevention and care” (1.62) as compared to respondents from middle- and high-income countries (1.15 and 1.27, respectively). Concerns about confidentiality reduced with the increasing age of respondents, while psychosocial support and couple counselling were considered more important with increased age, possibly reflecting greater responsibilities, family pressures or the challenges of maintaining long-term relationships. Sex workers responded that confidentiality was the most important factor and significantly higher than any other (1.89 for confidentiality, while their mean was only 1.58).

## Conclusions about HIV testing and counselling and community-based testing

Despite the reported lack of access to HTC, community respondents perceive advantages to various forms of community-based testing. This echoes the Harare community consultation findings, which emphasised the importance of redefining HTC as a key tool for enabling people to know their HIV status and for linking people living with HIV to care, treatment and support so as to realise universal access goals and the prevention benefits of treatment.<sup>21</sup> No single approach will be sufficient to support increased equitable HTC access, and countries will need to adopt an appropriate mix. However, as found during the Bangkok community consultation, effective HTC approach will require strengthening linkages to care, directly involving key populations, ensuring confidentiality, safeguarding individual choice without coercion or interference and facilitating disclosure.<sup>22</sup>

### Key findings from the e-survey and e-forums regarding HIV testing and counselling

- Current HTC access is not universal. Specific groups in different contexts facing ongoing barriers to access.
- Community respondents expressed varying preferences about community-based approaches to increasing HTC access, suggesting that people living with HIV and other key populations should be consulted to ensure that HTC responds to their needs and preferences, in order to ensure acceptability and effectiveness.

20. The range was from 2 (strongly agree) to -2 (strongly disagree).

21. Available at: <http://hivtreatmentoptimization.org/events/optimizing-hiv-treatment-access-and-retention-care-linking-community-level-interventions-0> (accessed 23 June 2013).

22. Available at: <http://hivtreatmentoptimization.org/events/optimizing-hiv-treatment-access-retention-care-bangkok-thailand-15> (accessed 23 June 2013).

## B. ARVs for prevention of HIV acquisition and transmission

### i. Treatment as prevention approaches

#### Key questions

- In your view, which groups of people living with HIV should have the option to start ART (regardless of their CD4 cell count) for reasons of prevention (i.e. start ART for treatment as prevention)? (ES39, n=452)
- What are the potential challenges and benefits of offering ART regardless of CD4 cell count? (ES41, n=447)
- How important will it be in your country to ensure the actions below with regards to treatment as prevention? (ES42, n=435)

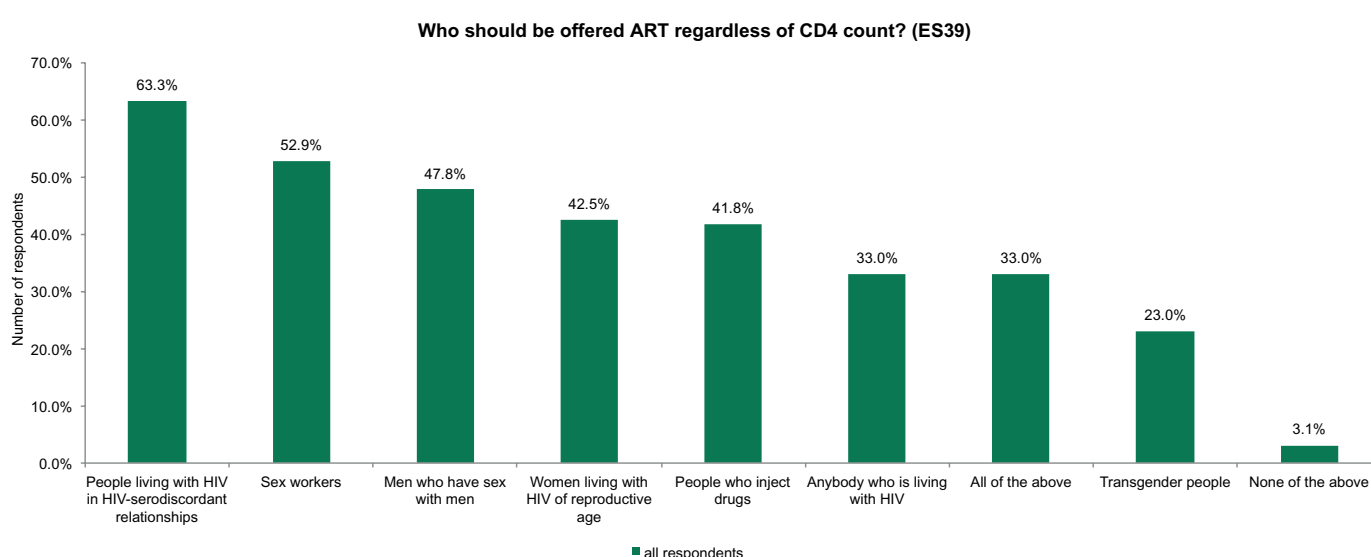


Figure 4. Who should be offered ART regardless of CD4 cell count? (n=452)

Community respondents tended to agree about which groups should be offered ART regardless of CD4 cell count. There were no statistical differences between people living with HIV and those not living with HIV, or between respondents from countries with different income status. The majority of respondents supported offering ART to people living with HIV in sero-discordant couples and to sex workers,<sup>23</sup> with MSM, women of reproductive age and people who inject drugs not far behind. E-forum contributors re-affirmed that early ART could benefit individuals in sero-discordant relationships or who also live with hepatitis B, and should be offered to key populations.

The middle ranking of women living with HIV of reproductive age in ES39 may reflect current practice and respondents' experience, rather than any contradiction of the strong preferences for Option B+ expressed elsewhere in the e-survey. The low ranking for transgender people may reflect a widespread lack of awareness and understanding of their vulnerabilities, needs and difficulties in accessing "trans-friendly" HIV services.

23. Community responses regarding key populations do not necessarily reflect the views of key populations themselves.

## Potential benefits of offering treatment as prevention

Community respondents acknowledged that earlier initiation of treatment makes economic sense and offers health benefits (because at higher CD4 cell counts the immune system is stronger and can recover quickly). They even noted that over the long term it may become less costly to treat people immediately than to wait for them to become sick and susceptible to opportunistic infections, with associated costs of care.

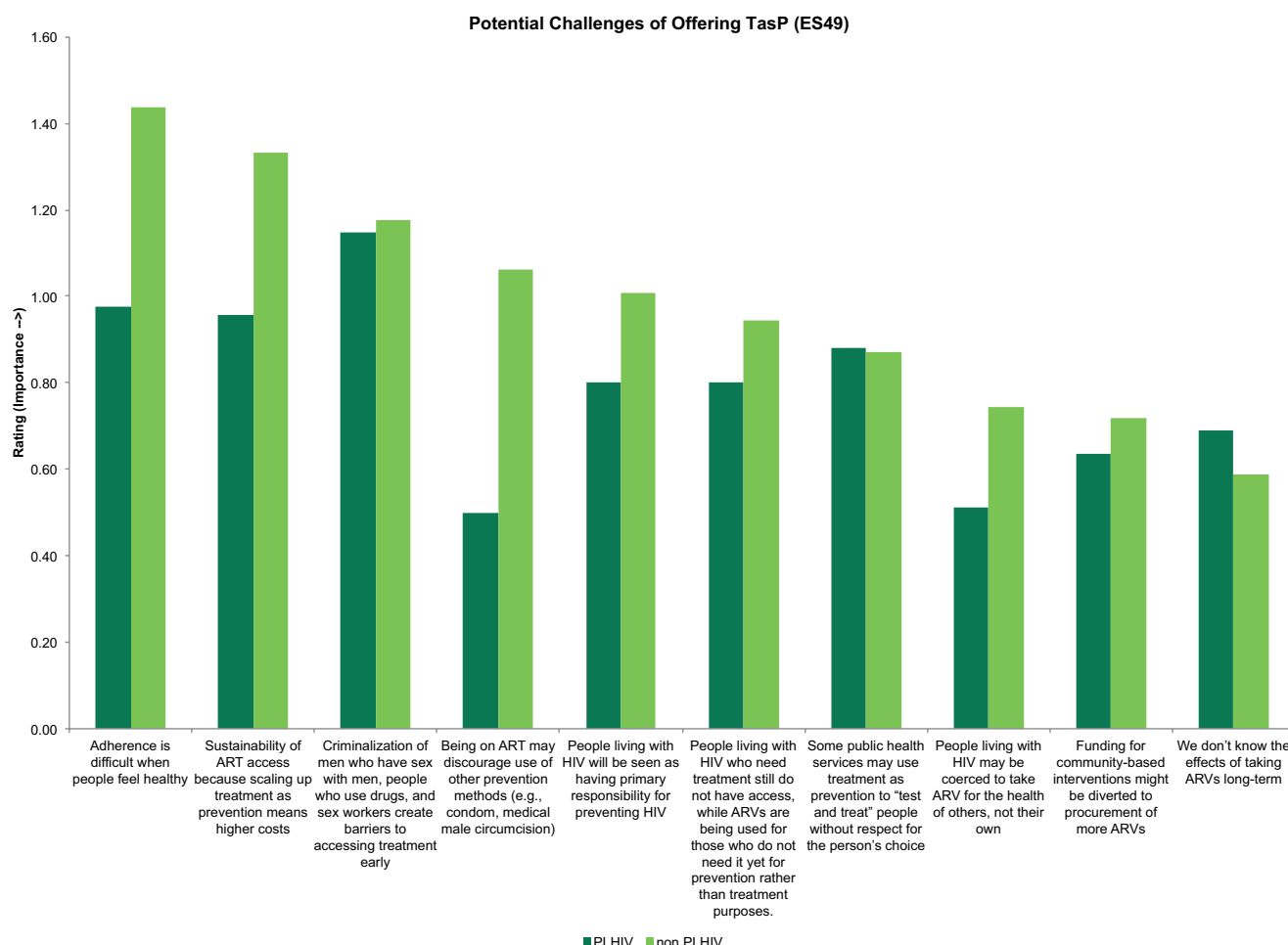


Figure 5. Potential challenges of offering treatment as prevention (n=447)<sup>24</sup>

Responses regarding the potential challenges of TasP differed between people living with HIV and those not living with HIV, possibly because people living with HIV were responding from their own knowledge and experience, while those not living with HIV were probably reflecting their own concerns and assumptions about TasP. In addition, respondents from high-income countries ranked several factors higher or lower than those from middle- and low-income countries. For instance, respondents from high-income countries agreed more strongly that "criminalization of men who have sex with men, people who use drugs, and sex workers" (1.43) are potential challenges to offering ART regardless of CD4 cell count, but only marginally agreed about "adherence difficulties" (0.95) and "discouraging the use of other prevention methods" (0.56). Respondents, particularly those not living with HIV (1.44), highlighted the difficulty of adhering to ARV treatment while feeling healthy as an important challenge of TasP. Male respondents were less concerned about the difficulty of adherence for people who are feeling healthy (1.00) than female respondents (1.37). Issues for women regarding stigma, disclosure and the costs of accessing ART may have contributed to this difference. Women highlighted concerns about adherence more than men, and about the possibility that being on ART might discourage use of condoms or male circumcision (which require active male involvement).

In addition, criminalisation of HIV transmission and exposure featured prominently as a barrier to TasP in both the e-survey and e-forums. Among different population groups, young people and people from key populations were most concerned about criminalisation. People who inject drugs and refugees/migrants were most concerned that people living with HIV who need treatment still do not have access, and that ARVs are nevertheless being used for prevention. People who inject drugs rated most factors higher than other population groups, possibly due to their low access to services overall.

24. The range was from 2 (strongly agree) to -2 (strongly disagree).



Community respondents raised concerns about long-term side effects of ARVs as a key consideration for people who wish to start treatment early. Additionally, respondents expressed concerns about possible resistance that could emerge from non-adherence. One e-forum respondent noted, "...People who are still relatively well ... might not put adherence in its proper perspective ... a lot more rigorous patient education on adherence [is needed]." Stigma and discrimination experienced by people living with HIV and other key populations already serve as a barrier to adherence, not to mention access to treatment in the first place. One e-forum contributor said, "even with current cut-offs we are failing to adequately address adherence issues at an individual level and operational issues at the level of health systems", and added that this is resulting in an increase in drug resistance.

Consequently, community respondents identified that adherence for those initiating treatment early requires adherence support and building treatment literacy of patients at service and community levels. They also acknowledged the economic benefits of enabling nurses or community-based counsellors to support ART adherence, at a fraction of the cost of a doctor. In addition, community respondents also discussed the impact of TasP on health systems. For instance, one e-forum respondent commented, "How wise is it to increase the CD4 count threshold when we haven't properly solved all treatment problems as they stand? Would health (and community) systems be able to cope?" This highlights the need to ensure that health systems are strengthened to match demand for HIV services, including TasP.

## Essential actions when offering treatment as prevention

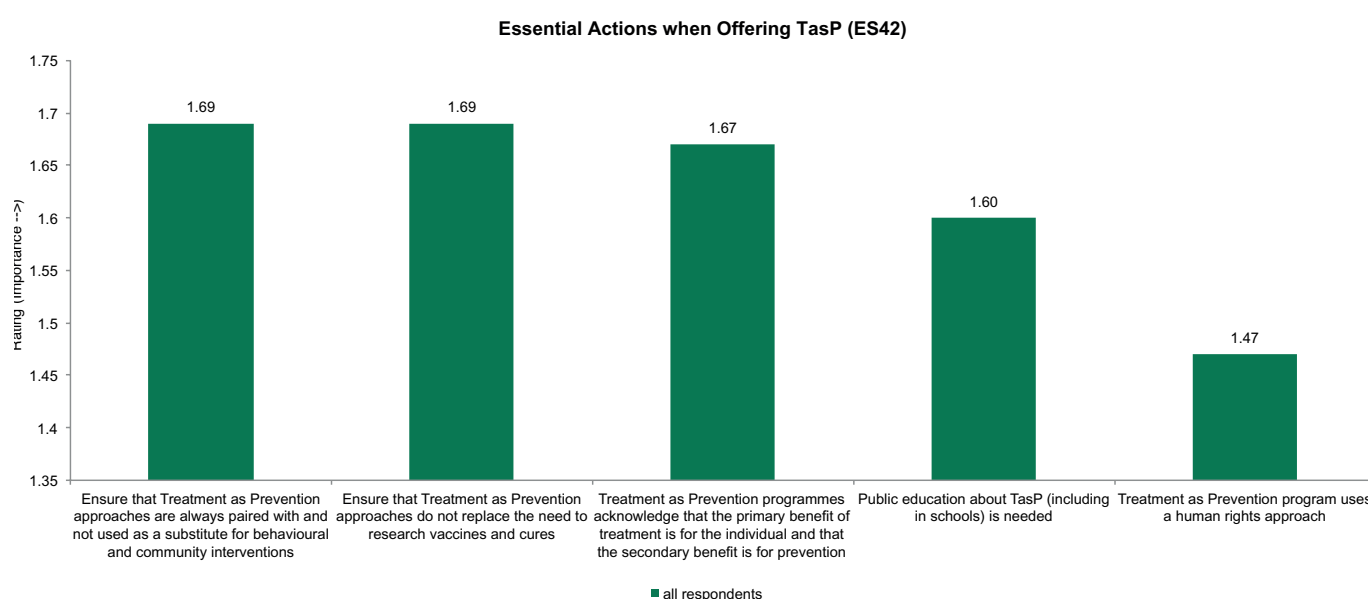


Figure 6. Essential actions when offering treatment as prevention (n=435)

Respondents identified many essential actions that national programmes should take to ensure that programming for TasP would be successful. These include implementing TasP alongside behavioural and community interventions, rather than in isolation (1.69), and ensuring that other biomedical vaccine research is not neglected on account of TasP (1.69). Respondents also highlighted the need to acknowledge that the primary benefit of treatment is to the individual, and that the secondary benefit is for prevention (1.67), and to ensure that literacy related to TasP is strengthened (1.60). Respondents frequently called for TasP programmes to use a human rights approach (1.47).

Overall, and in comparison to other groups, transgender respondents in the survey rated all five actions as very important, for reasons that are not readily apparent. No other significant differences in the survey responses were noted. In terms of the forums, participants reminded each other that the doctor's role is to make recommendations and motivate the patient, whereas it is the patient's responsibility to make their own decision about when to begin treatment, providing they have the appropriate level of treatment education.

## Conclusions about treatment as prevention

Community respondents generally agreed that key populations should have the personal choice to access TasP. Despite the known benefits of TasP, respondents highlighted many important barriers, including criminalisation of key populations and adherence difficulties, among others. Finally, respondents identified a number of key actions that national HIV programmes should implement to ensure that TasP programming is successful, including community and health system strengthening to ensure that structures exist and are properly equipped to support TasP.

## Key findings from the e-survey regarding treatment as prevention

- TasP approaches should always be paired with and not replace behavioural and community interventions. They should be part of a combination approach, including behavioural, biomedical and structural interventions.
- Informed choice is critical to a rights-based approach to TasP. Doctors can facilitate choices by offering recommendations and motivating patients, so that they can make their own decisions about when to begin treatment.
- Stigma and discrimination experienced by people living with HIV and other key populations which is a barrier to access to treatment and a source of potential human rights violations, should be eliminated as part of combination approaches in support of TasP. Respondents emphasised the critical role of communities in fighting stigma and assisting people to access services.
- Investment in community and health system strengthening is essential to ensure that structures exist and are properly equipped to support TasP

## ii. Pre-exposure prophylaxis

### Key questions

- Which groups of people who are currently HIV negative should have the option to use PrEP? (ES45, n=417)
- Do agree that the following are barriers to PrEP? (ES46, n=427)

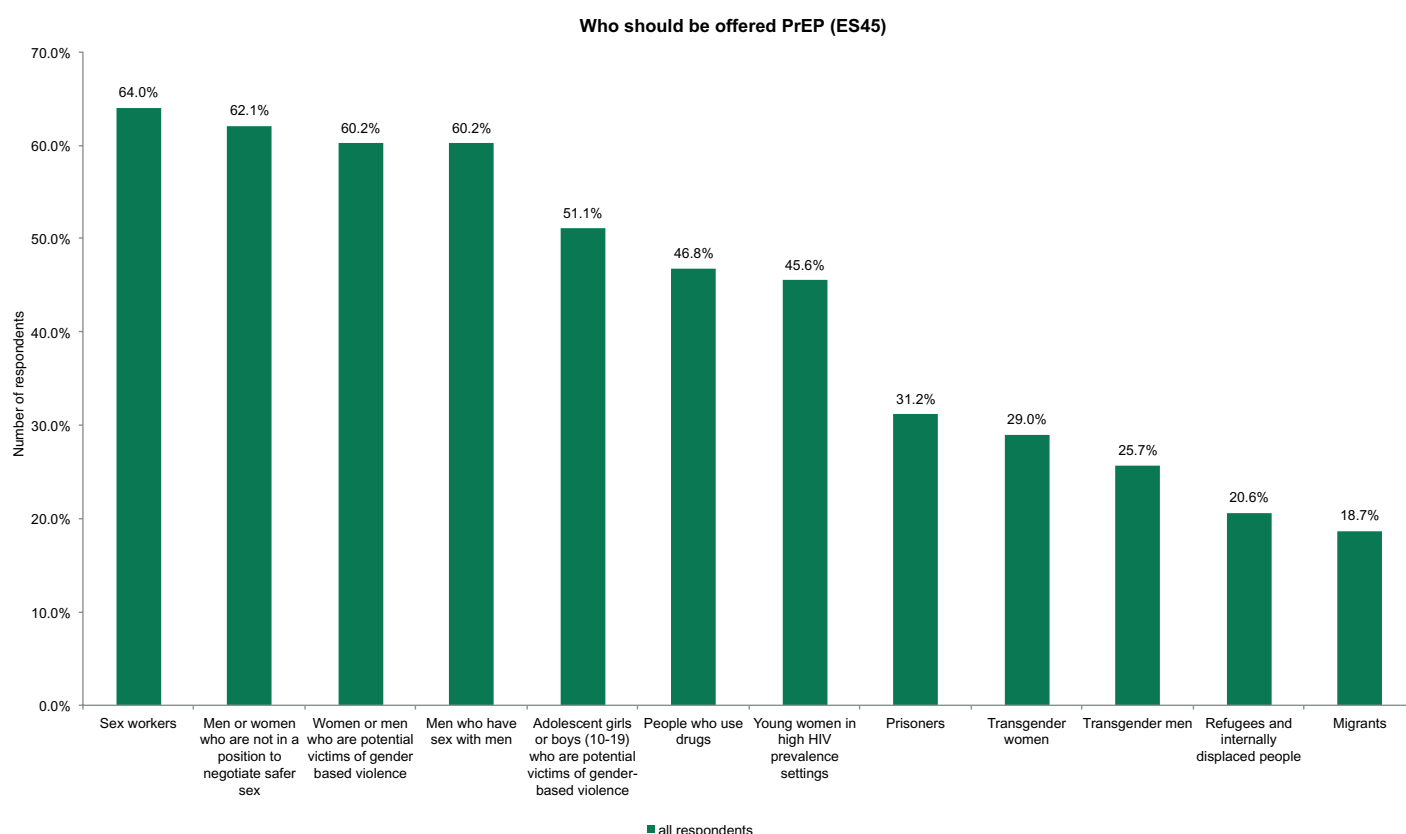


Figure 7. Groups that should be offered pre-exposure prophylaxis (n=417)

In terms of who should be offered PrEP, community respondents most frequently chose sex workers (64.0%), men or women not in a position to negotiate safer sex (62.1%), female or male potential victims of gender-based violence (60.2%), MSM (60.2%), and adolescent girls or boys who are potential victims of gender-based violence (51.1%). However, community responses regarding key populations do not necessarily reflect the positions of key populations themselves. For instance, a majority (82%) of MSM felt that MSM should be offered PrEP. Consequently, in interpreting these findings, it is important to remember that some key population groups may have received lower priority rankings due to a low level of awareness among community respondents of their needs.

Respondents identified the cost of PrEP as the most important potential barrier to accessing PrEP (if individuals will be required to pay for it). This view was strongly held among women, people not living with HIV and respondents from low-income countries. However, transgender people and people living with HIV strongly agreed that stigma and discrimination are the most important barriers to accessing PrEP. E-forum respondents wondered how realistic it would be to expect someone who was not sick and did not have HIV to adhere to the proposed treatment regimen. One participant (English e-forum) said “PreP for gonorrhoea has been available for half a century ... and has not been recommended as a public health measure. Why rush to push pre-exposure prophylaxis for HIV?”

### Key findings from the e-survey regarding pre-exposure prophylaxis

- Specific groups of people should have the option to use PrEP, particularly those unable to negotiate safer sex, sex workers, MSM and potential victims of gender-based violence.
- Providing access should complement, rather than hinder, universal access to ART for those who are eligible.
- Concerns regarding adherence highlight the need for comprehensive education to strengthen adherence to PrEP regimens, and address concerns related to potential toxicities of PrEP.
- The roll out of PrEP requires in-depth, appropriate consultations by the communities who will be given the option to use these technologies in order to ensure its acceptability and effectiveness.

### iii. Management of postnatal care, including infant feeding

Focus group discussion participants in Malawi and Uganda raised the issue of breastfeeding in the context of Option B+. The majority of focus group discussion participants were convinced of the benefits of being able, with Option B+, to breastfeed their children up to the age of two years old. With Option A or B, they had to stop breastfeeding at six months and many children had died of malnutrition, despite having been born HIV negative. Additionally, mothers and children had experienced stigma and discrimination because they were clearly identified as HIV positive when they did not breastfeed. Participants were also happy that longer breastfeeding meant a related reduction in household expenditure from not having to buy milk or formula, or treatment for opportunistic infections. However, participants in both countries remain unclear about current recommendations regarding the length of time when breastfeeding should be exclusive, and when and how solid foods could be safely introduced.<sup>25</sup>

### Key findings from focus group discussions regarding infant feeding

- Despite general support for breastfeeding, participants are still unclear about current recommendations on breastfeeding duration, exclusiveness, and when and how solid foods should be introduced.
- Consistent messaging by all sectors at *all* levels is needed to ensure that communities and healthcare providers receive and make use of accurate information, and that the 2013 ARV Guidelines and related breastfeeding guidelines are well understood.

25. For a fuller discussion on breastfeeding in the context of prevention of mother-to child transmission, see GNP+ (2013), Option B+: understanding perspectives/experiences of women living with HIV. Available at: <http://www.gnpplus.net/>

## C. Starting first-line ARVs – when and with what?

### i. Adults and adolescents

#### When to start

##### Key questions

- When should people living with HIV be offered ART? (ES15, n=696)
- Which people or populations living with HIV should be offered earlier ART regardless of their CD4 cell count? (ES16, n=676)
- Should the threshold at which ARV is initiated be raised from 350 to 500? Why or why not? (EF)

A majority of community respondents said that people living with HIV should be offered ART when their CD4 cell count is above 350 cells/mm<sup>3</sup> but below 500 cells/mm<sup>3</sup> (51.0%).<sup>26</sup> Additionally, respondents were of the view that other considerations for offering ART include: 1) when people have tuberculosis (TB) or hepatitis B or C co-infections (48.1%); 2) when people are seriously ill regardless of CD4 cell count or according to WHO staging (47.2%); and, 3) when they feel ready to start ART (43.2%). Some e-forum respondents felt that the threshold for ART initiation should remain at CD4 cell count of 350 cells/mm<sup>3</sup> in resource-limited settings, except for people living with HIV in sero-discordant relationships and all key populations.

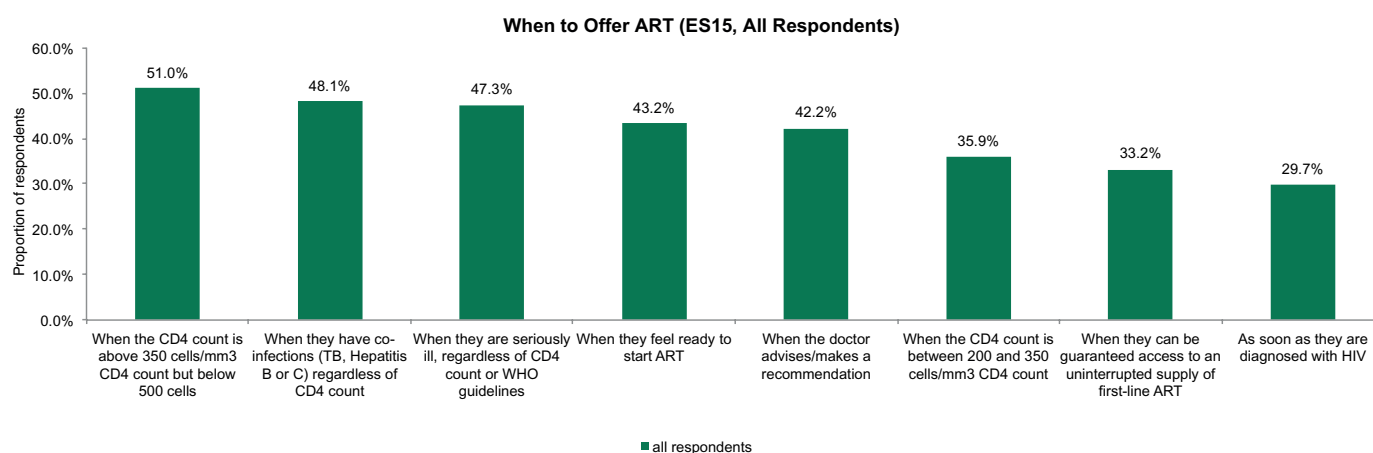


Figure 8. When to offer treatment to people living with HIV, all respondents (n=696)

26. This question was ambiguously formulated. Of the ten options available, four specified possible threshold levels and another stated, "When they feel ready to start ART". Respondents may have understood the options either as the optimal time to start or the different circumstances in which to start. If respondents could have chosen only one option, it is possible that the number choosing CD4 of 350–500 cells/mm<sup>3</sup> might have been even higher.

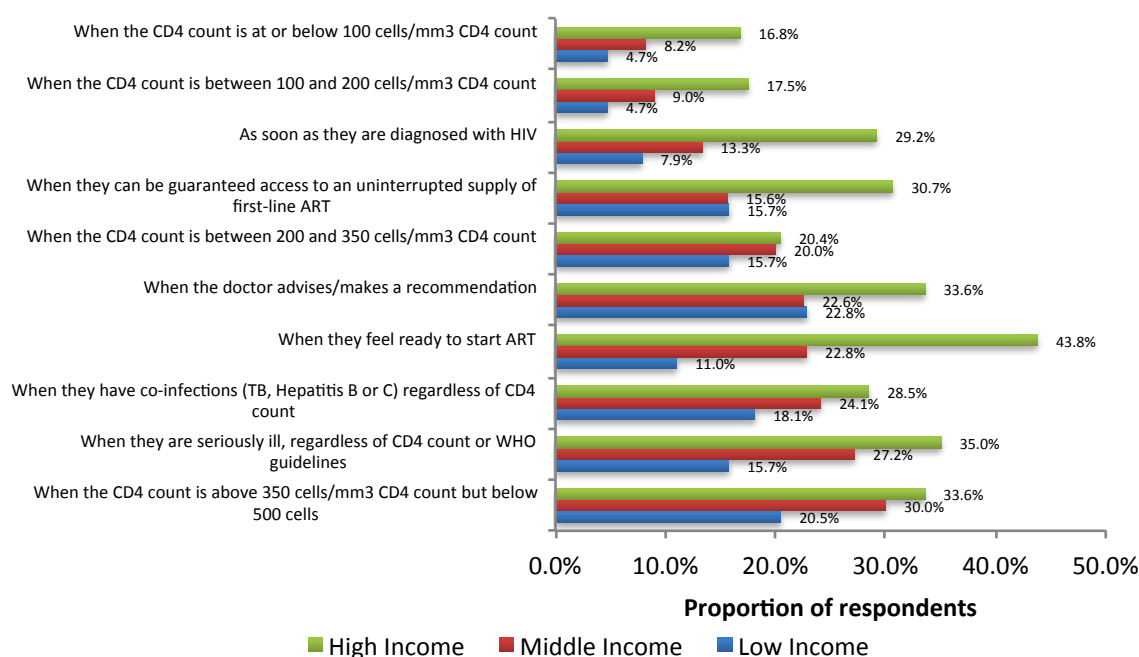


Figure 9. When to offer treatment to people living with HIV, country income status (n=606)

Respondents from countries with varying income status expressed some differences regarding the relative importance of the above factors in determining when people living with HIV should start ARV. Respondents from high-income countries ranked personal readiness to start ART (43.8%, highest rank) and serious illness (35.0%) higher, while respondents from low-income countries ranked “when the doctor advises/makes a recommendation” (22.8%, highest rank) and co-infections (18.1%) higher. Some of the differences may be related to varying experiences of opportunistic infections such as Tuberculosis (TB): in low-income countries serious opportunistic infections such as TB might be more common and therefore possibly less alarming or unexpected. Also, it may be that people in low-income settings generally have fewer sources of information on health and HIV and are therefore likely to be more reliant on their doctors for decision-making about ART.

**Table 1: Advantages and disadvantages of offering lifelong ART during pregnancy, regardless of CD4 cell count (e-forum and focus group discussion)**

For individuals initiating ART at higher CD4 cell count thresholds	
Advantages	Disadvantages
<ul style="list-style-type: none"> <li>Immune function is still viable and ought to recover quickly</li> <li>Reduces likelihood of progression to AIDS</li> <li>Reduces incidence of opportunistic infections</li> <li>Reduces incidence of new infections for people vulnerable to HIV</li> </ul>	<ul style="list-style-type: none"> <li>Individual may not be willing to start ART/maintain adherence at a higher CD4 cell count if they do not perceive themselves as sick</li> <li>Long-term ART is associated by many people living with HIV with morbidity due to serious side effects</li> <li>Safer drugs with fewer side effects may not be available</li> </ul>
For health services offering ART at higher CD4 cell count thresholds	
Advantages	Disadvantages
<ul style="list-style-type: none"> <li>Value of TasP</li> <li>Less costly to treat people straight away than to wait for them to fall ill</li> <li>Mirrors treatment of other diseases and thus assists in normalising HIV</li> <li><i>“The benefits of early treatment should be available to people equally in either rich or developing countries”</i> (Arabic e-forum participant)</li> </ul>	<ul style="list-style-type: none"> <li>Inadequate human and financial resources to manage increased workload (universal coverage has still not been achieved even at a CD4 cell count of 250 cells/mm<sup>3</sup> or less)</li> <li>Risk that countries might purchase poor-quality medicines to cut costs</li> </ul>



Regarding which people or populations living with HIV should be offered earlier ART regardless of their CD4 cell count, pregnant women (89.8%), people in sero-discordant relationships (71.9%), and sex workers (55.8%) ranked highest among all respondents. This may reflect acceptance of existing guidance and potentially respondents' levels of knowledge (see Figure 10). Transgender people, people over 50 years of age, and people with HIV-2 scored lowest, probably reflecting general levels of knowledge and understanding of these population groups.

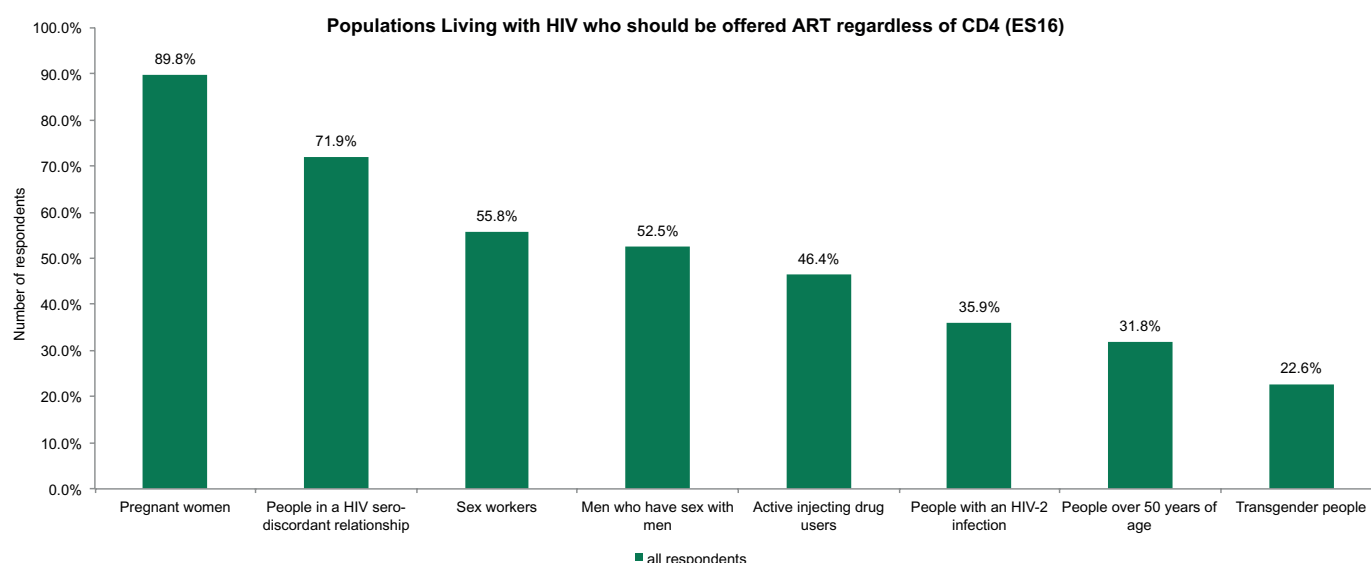


Figure 10. Populations living with HIV who should be offered ART regardless of CD4 cell count (n=676)

**Role of healthcare providers in treatment initiation:** E-forum respondents agreed that individual patients are best placed to decide when to initiate ART, with adequate information and guidance from the healthcare team. Respondents noted the importance of ensuring that individuals are adequately informed and do not initiate treatment under pressure, citing studies which have shown that this could lead to non-adherence. One respondent specified, “The role of the health worker should be primarily to educate people and get their ‘buy-in’.” Another noted, “A physician should only make recommendations and motivate patients.”

## What to start

### Key questions

- If you are taking d4T, are you willing to continue on it? (ES17, n=572)
- In what situations should d4T still be used in a country? (ES18, n=654)

A majority of respondents (72.7%) preferred not to continue with d4T for treatment because of current or future side effects.<sup>27</sup> Among the few who thought use of d4T might continue, most indicated that it requires regular monitoring (8.4%) or should only be offered for a short time (7.0%). 30% of people living with HIV who responded to the e-survey indicated either that no one was on d4T in their setting or that they did not know if anyone was still on d4T in their setting. Some e-forum respondents mentioned that d4T was still in use, and that their national guidelines still specified outdated ARVs.

Respondents felt that d4T may continue to be used by those already on it who are tolerating it well (32.9%) or for third-line or salvage therapy (31.8%). Other respondents, in particular people living with HIV, preferred stopping its use altogether (31.2%), possibly due to personal experience or knowledge of d4T's side-effects. Few thought that the low cost (8.4%) or the need to use up existing stocks of d4T already in country (10.1%) should determine whether d4T is made available.

27. Stavudine is no longer recommended as a first-line ARV by WHO.

## How should ART be offered?

### Key questions

- How important is it to have the following available to you? (ES19, n=624)
- Do you agree with the following statements on advantages of a once-daily regimen? (ES20, n=633)
- Do you agree with the following statements about advantages of co-blister packaging? (ES21, n=623)
- Should a once-daily approach (using fixed dose combinations (FDC) or co-blister) be adopted as the preferred treatment strategy? Why or why not? (EF)

Most respondents believed it is very important to have one pill a day containing all drugs (77.9%). E-forum respondents felt that a once-daily regimen is convenient to carry and administer, and is important for those who are not ready to disclose their status. They found 12-hour dosing to be problematic, particularly when fasting for religious reasons, and could be addressed by a once-daily regimen. They felt it important to have a tenofovir (TDF)-based first-line regimen available with lamivudine (3TC)/ Emtricitabine (FTC) and efavirenz (EFV) to those in resource-limited settings at a low cost and with easy storage conditions.

A once-a-day regimen with more than one pill was less favoured, but still considered important (56.8%), while co-blisters were viewed as less important (41.67%). Respondents said, “Co-blister packaging implies that the patient still needs to take more than one pill ... the once-daily regimen is really favourable ... because it can lower the pill-burden.” The advantage of co-blisters in helping to keep pills clean and dry was considered more important than simplified treatment for easier adherence, but still not rated as high as all three advantages of once-daily doses.

### Key findings from the e-survey and e-forums regarding first-line ART for adults and adolescents

- The majority of respondents support offering ART to people living with HIV when their cell count is above 350 cells/mm<sup>3</sup> CD4 but below 500 cells/mm<sup>3</sup>. The majority of respondents supported offering ART to pregnant women and sero-discordant couples regardless of their CD4 cell count.
- Personal readiness continues to be an important aspect of treatment initiation. Individual patients are best placed to make a decision about when to initiate ART, once adequately informed.
- People living with HIV want simpler, more tolerable and effective ARVs, preferably as ‘once-daily’ dosing, and as a single pill.

## ii. People with TB-HIV and/or hepatitis B or C co-infections (CD4 >350 cells/mm<sup>3</sup>)

### Key questions

- When people living with HIV are diagnosed with TB co-infection (ES23, n=629) or hepatitis B/C co-infection (ES24, n=629), what do you think should be offered to them?

Respondents felt that treatment for TB-HIV, hepatitis B-HIV, and/or hepatitis C-HIV co-infections (88.2%) should be offered, together with ART (68.2%), information and counselling for family members (62.2%), and referrals to peer support (49.9%). These responses tend to confirm the community's belief that people with these co-infections need a comprehensive package of interventions, including social and behavioural as well as biomedical approaches. There was no statistical difference between people living with HIV and those not living with HIV in terms of this issue.

### Key point – ART for people with co-infections

- When people living with HIV are diagnosed with TB, hepatitis B or hepatitis C, they need a combination of interventions with a package of services and support. No *single* intervention alone will be effective. Thus, the 2013 ARV Guidelines should stress the need for multidisciplinary and cross-sector teams supporting people living with HIV, including those with co-infections.

### iii. Pregnant women and prevention of mother-to-child transmission

#### Key questions

- If you were pregnant and living with HIV, which option would you prefer? (ES26, n=439; people living with HIV=230)
- If Option B+ is to be successfully implemented in your context, which are the most important issues to address?<sup>28</sup>
  - ART-related issues (ES27, n=543)
  - service capacity/quality-related issues (ES28, n=543)
  - social/legal issues (ES29, n=619).
- If I was given the option to continue ART when there is no longer a risk of transmission to my child, I would need to consider the following. (ES30, n=532)

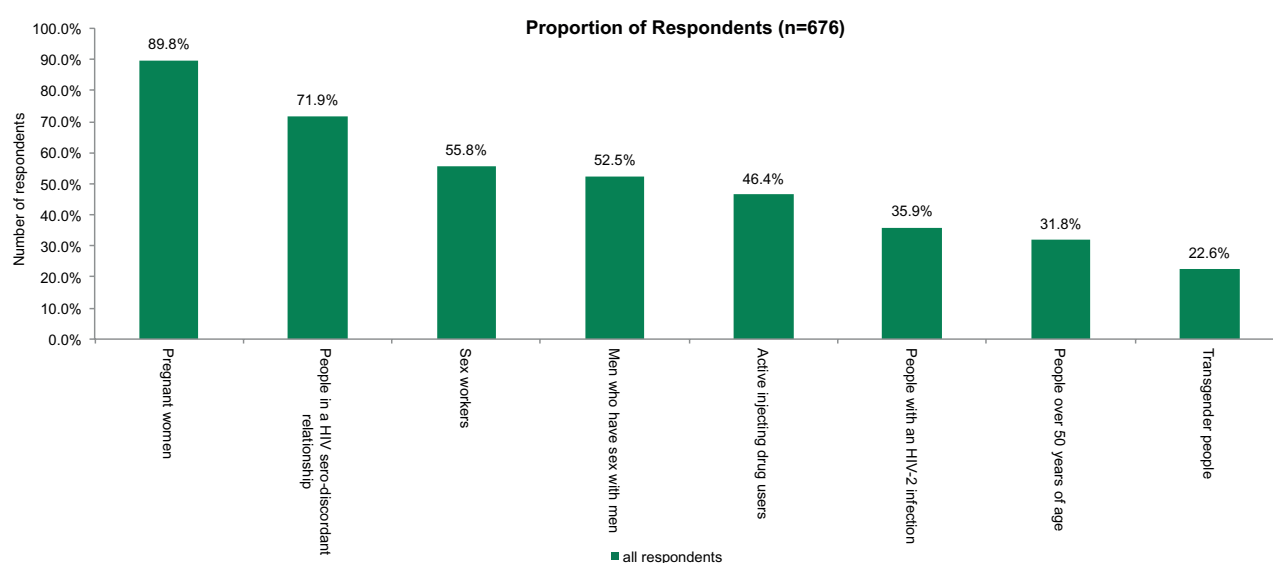


Figure 11. Respondents who support offering pregnant women ART regardless of their CD4 cell count (ES16, n=676)

28. The range was from 2 (very important) to -2 (very unimportant).

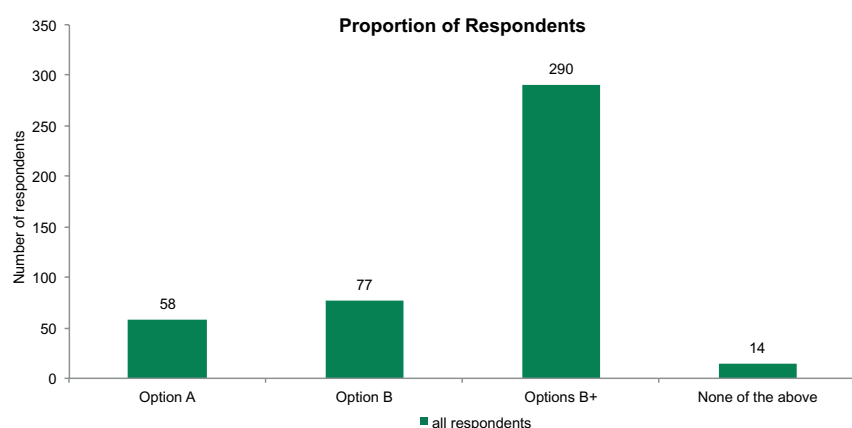


Figure 12. Preference for lifelong ART in pregnant women (Option B+) (ES26, n=439)

Community respondents agreed that pregnant women should be offered ART regardless of CD4 cell count (88% of people living with HIV; 90% of all respondents) and strongly preferred Option B+<sup>29</sup> (64.4% of people living with HIV; 66.1% of all respondents), which correlates with the e-forum and focus group discussion findings. Pregnant women represented only 4.8% of responses regarding the preference for Option B+, few of them identifying as living with HIV, thereby limiting generalisability to all pregnant women living with HIV.

Focus group discussion participants asked, “Whose ‘option’ is it?” They felt that the term “Option B+” gave a misleading impression that women themselves would be allowed to make an informed choice on which approach would be best for them. In practice, a national decision was made about which protocol to offer women, so women were presented with Option B+ as the only method available. While many e-forum respondents agreed that Option B+ should be the only protocol available, some felt that countries should choose the protocol depending on their socio-economic context, but that acceptance of this should also be a personal choice for individuals.

Community respondents acknowledged many benefits associated with Option B+, but also identified concerns. Malawi focus group discussion participants shared that under Option B+, many women were expected to start ART as soon as they received a positive HIV result, or at least within a few days, without sufficient psychosocial support, time to think through the implications, or prepare for disclosure to partners. One e-forum respondent said, “It has been that they test and treat immediately ... Women have challenges because if they go out of the hospital and with medication they can’t think of ways of how to inform their husbands so they take [ARVs] behind their husband’s back and some of them don’t take their medication.” Respondents advised that “a lot more rigorous patient education on adherence” would be required to address individual-level concerns.

29. Option B+ was described as “triple ARV treatment for all pregnant women living with HIV regardless of CD4 count as soon as HIV diagnosis is confirmed and ART is continued for life; provide infants with daily nevirapine (NVP) or AZT from birth through age 4-6 weeks regardless of infant feeding method.”

**Table 2. Lifelong ART for pregnant women living with HIV: benefits and concerns (focus group discussion and e-forum)**

Individuals	
Benefits	Concerns
<ul style="list-style-type: none"> <li>• May increase access to ART (irrespective of CD4 cell count)</li> <li>• May increase breastfeeding period option and reduce infant mortality and household expenditure on infant feeds</li> <li>• Could reduce stigma towards mother and child (breastfeeding, healthier appearance, child is HIV negative)</li> <li>• Possibility of having more children</li> <li>• May reduce fear of resistance due to stopping and starting ARVs</li> <li>• Encourages disclosure, behaviour change, testing and ARV uptake</li> <li>• Enables natural childbirth</li> <li>• Starting treatment at higher CD4 cell counts may lead to better treatment outcomes</li> </ul>	<ul style="list-style-type: none"> <li>• Initiation of ART with high CD4 cell count (side effects/toxicity, adherence, especially when young)</li> <li>• Risk of coercion to begin ART</li> <li>• May discourage disclosure (because individual appears healthy); alternatively, may force disclosure (due to presence of ARVs that are brought home)</li> <li>• May expose individual to violence</li> <li>• Lack of information, support and counselling</li> <li>• Incentive to get pregnant to access ARVs</li> <li>• Concerns about resistance and need for second and third line earlier</li> </ul>
Child	
Benefits	Concerns
<ul style="list-style-type: none"> <li>• Babies born HIV negative</li> <li>• Could reduce stigma to mother and child (breastfeeding, healthier appearance, child is HIV negative)</li> </ul>	
Partner	
Benefits	Concerns
<ul style="list-style-type: none"> <li>• Sero-discordant partners are protected (TasP)</li> </ul>	<ul style="list-style-type: none"> <li>• Risks around forced disclosure</li> <li>• Concerns about equity of Option B+ when partners need and cannot access ARVs</li> <li>• Male involvement interpreted as a requirement for access to ARVs</li> <li>• Risk of gender-based violence could increase</li> <li>• May discourage condom use by male partners</li> <li>• Lack of access to ARVs may reduce male involvement</li> </ul>
Health system	
Benefits	Concerns
<ul style="list-style-type: none"> <li>• Simplifies efforts to prevent mother-to-child transmission of HIV</li> <li>• Prevent delays from starting treatment due to CD4 cell counts</li> </ul>	<ul style="list-style-type: none"> <li>• ARV stock outs and weak health systems (particularly in Uganda)</li> <li>• Women living with HIV and communities are not being consulted</li> <li>• Potential inequity if pregnant women are accessing ARVs before other eligible people living with HIV.</li> <li>• Cost</li> <li>• Affordability</li> <li>• Sustainability</li> </ul>

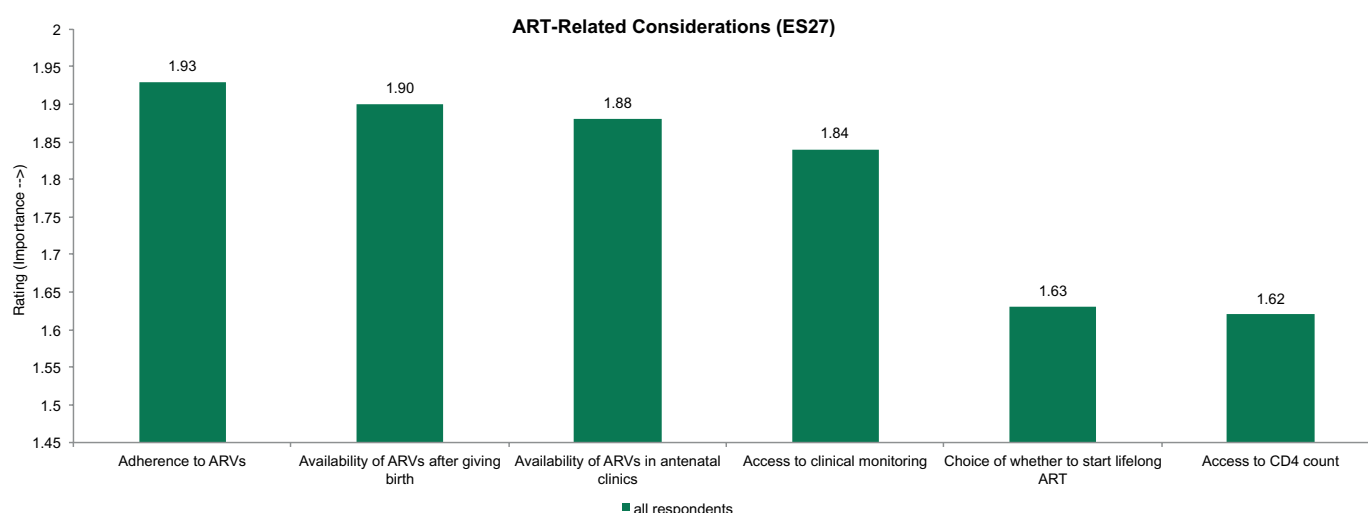


Figure 13. ART-related considerations for Option B+ (n=543)



Community respondents ranked the following ART-related issues as important for the successful implementation of Option B+: adherence to ARV; ARV availability after birth; ARV availability at antenatal clinics; and access to clinical monitoring (type of monitoring not specified). There were no statistical differences between people living with HIV and those not living with HIV. Focus group discussion participants were concerned about a longer period of ART exposure, which could mean more side effects and a possible need for second- and third-line ART if they start first-line sooner.

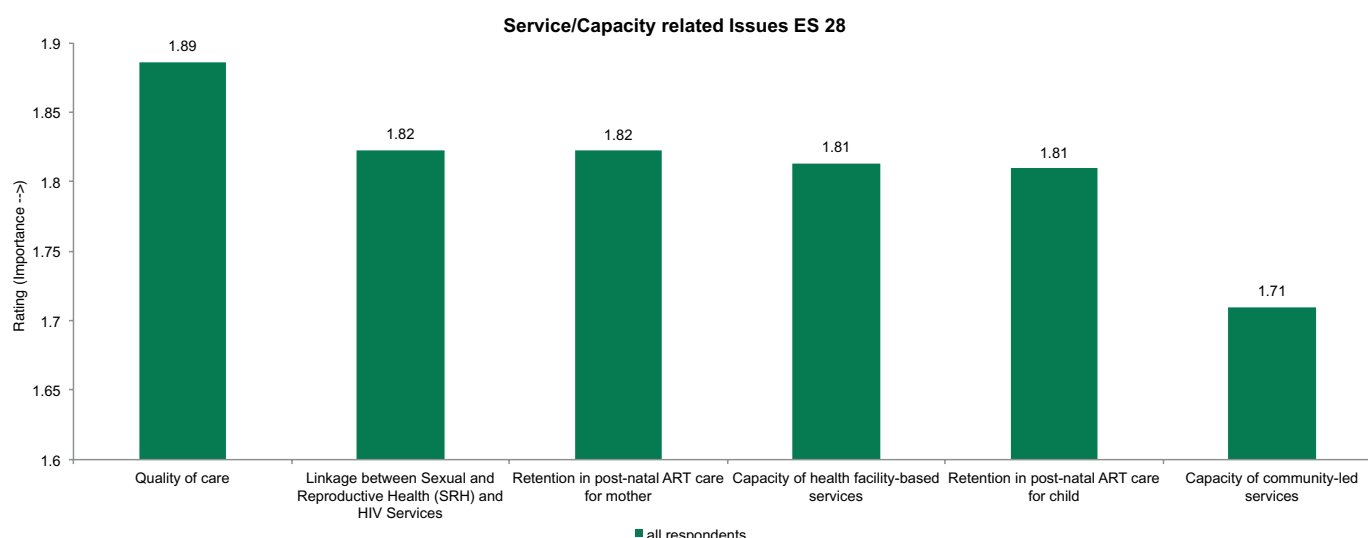


Figure 14. Service/capacity-related considerations for Option B+ (n=543)

Respondents ranked the following service capacity/quality-related issues as important for the successful implementation of Option B+: quality of care; linkage between SRH and HIV services (including ART); retention in postnatal ART care for mothers; capacity of health facility-based services; retention in postnatal ART care for children; and the capacity of community-led services. There were no notable differences based on HIV status of respondents.

E-forum respondents added that decentralisation and strengthening linkages between community and health systems would be critical to the effective provision of Option B+ and PMTCT care. They suggested: (1) initiating relevant components of PMTCT via outreach services at the community level, with linkages to a health facility; (2) training communities to ensure better linkages; (3) strengthening involvement of community-based organisations, groups and associations, and of the non-governmental organisations that work with them, in PMTCT provision; and (4) implementation of policy or protocol to support coordination between ministries of health and community-based organisations. Some community respondents also emphasised the need to provide PMTCT care in facilities that serve people who inject drugs or other key populations, as well as policies enabling the integration of HIV and SRH services.

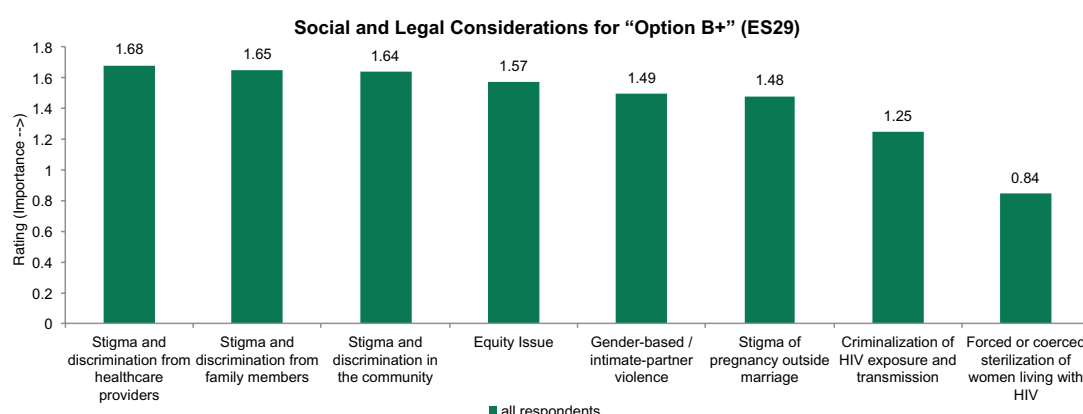


Figure 15. Social and legal considerations for Option B+ (n=619)

Community respondents ranked social and legal issues as important to overcome for the successful implementation of Option B+, with stigma and discrimination from healthcare providers (1.75 PLHIV; 1.70 non-PLHIV), family members (1.68 PLHIV; 1.72 non-PLHIV) and within the community (1.68) ranked as most important.

Thus, Option B+ implementation must be supported by efforts to tackle the stigma and discrimination that affect pregnant women and women more generally at multiple levels. This may require national legal and policy change.

The inequity of offering lifelong ART only to pregnant WLHIV was also seen as an important barrier (1.67 PLHIV; 1.56 non-PLHIV). Focus group discussion participants commented on the potential risk of increased exposure to gender-based violence due to unintentional disclosure when a women returns home with ARVs (prescribed to protect her and her child's health). E-forum and focus group discussion participants explained that the inequity of non-pregnant women living with HIV remaining without ART access (whether because of eligibility criteria or stock-outs), together with potential discouragement of male involvement due lack of ART access, and re-infection by partners who are not on treatment, could be a barrier to successful implementation of Option B+. An e-forum respondent said, "Non-involvement of male partners ... denies [pregnant women] the opportunity to get tested and treated. This is due to a lack of national strategies or programming to increase the involvement of men." To begin remedying these barriers, national strategies or policies are needed to encourage appropriate male involvement in PMTCT, although it should not be imposed as a condition for accessing PMTCT.<sup>30</sup>

Although criminalisation of HIV exposure and transmission, as well as forced or coerced sterilisation of women living with HIV, were ranked as marginally less important, they remain important human rights concerns in settings where criminalisation and coerced sterilisation still occur.<sup>31</sup>

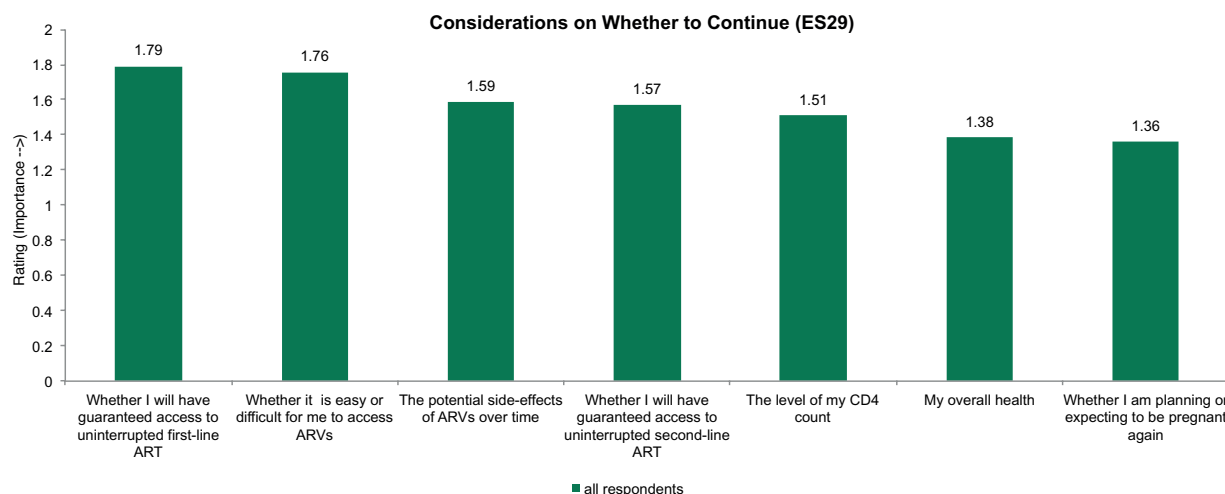


Figure 16. Considerations on whether to continue on ART (n=532)

Community respondents indicated that when there is no longer a risk of HIV transmission to the child, uninterrupted access to first-line ART and ease of accessing ARVs are among the most important considerations in determining whether or not women living with HIV continue on ART. Women living with HIV also considered their CD4 cell counts as an important consideration (1.55). Focus group discussion participants shared this view, since they understood CD4 cell counts to be measure of how healthy they are. One focus group discussion participant stated, "Me personally, after giving birth if my CD4 was high, I would stop those drugs." This differed from community respondents overall, who considered the potential side effects over time as the next most important consideration (1.59). These results indicate a difference between the concerns of women living with HIV on one hand and the overall assumptions of men living with HIV and people not living with HIV on the other hand, concerning what is important for women living with HIV. If postnatal women living with HIV experience or perceive limited access to ART and CD4 cell counts, there may be a greater risk of non-adherence or loss to follow-up. The factors identified by women living with HIV in particular should therefore be prioritised in programming and service delivery.

30. GNP+ and ICW (2013). "Some Malawi FGD participants reported that they needed to bring a male partner to their appointments to receive care. Some had paid men who were not their partners to attend the appointment with them."

31. Open Society Foundations (2013), Against her will: forced and coerced sterilization of women worldwide. Available at: <http://www.opensocietyfoundations.org/sites/default/files/against-her-will-20111003.pdf> (accessed 23 June 2013).

## Key findings from focus group discussions, e-survey and e-forums regarding lifelong ART for pregnant women and prevention of mother-to-child transmission (Option B+)

- Community respondents support offering ART to pregnant women living with HIV regardless of their CD4 cell count, and expressed a preference for “Option B+.”
- For the successful implementation of Option B+, many ART-related issues must be addressed, including adherence, ARV availability after birth and at antenatal clinics, and access to clinical monitoring.
- For the successful implementation of Option B+, many service capacity and health system issues must be addressed, including ensuring that the continuum and quality of care is not compromised, but is strengthened as new recommendations come in; linkage between SRH and HIV services (including ART); retention of mother and child in postnatal ART care; capacity of health facility-based services; capacity of community-led services; PMTCT in facilities that serve people who inject drugs or other key populations; and integration of HIV and SRH services. National strategies or policies are needed to encourage male involvement in PMTCT, although it should not be imposed as a condition for accessing PMTCT. Where health systems are weak, implementation of Option B+ would need to be supported by health and community system strengthening efforts to ensure systems are able to cope with demand and provide effective support for adherence.
- For the successful implementation of Option B+, many social and legal issues must be addressed, including stigma and discrimination (from healthcare providers and family members, and from within the community); inequity; gender-based violence; male involvement; HIV criminalisation; and forced sterilisation.
- Important consideration for women living with HIV on whether or not to continue ART after the risk of transmission to the child has passed, include uninterrupted access to first-line ART, ease of accessing ARVs, and personal CD4 cell count. The factors identified by women living with HIV should be prioritised in programming and service delivery.

## iv. ART for children

### When to start (children)

#### Key question

- At what age do you think children should be offered ART regardless of their CD4 cell count? (ES31, n=447) Why? (ES32, n=463)

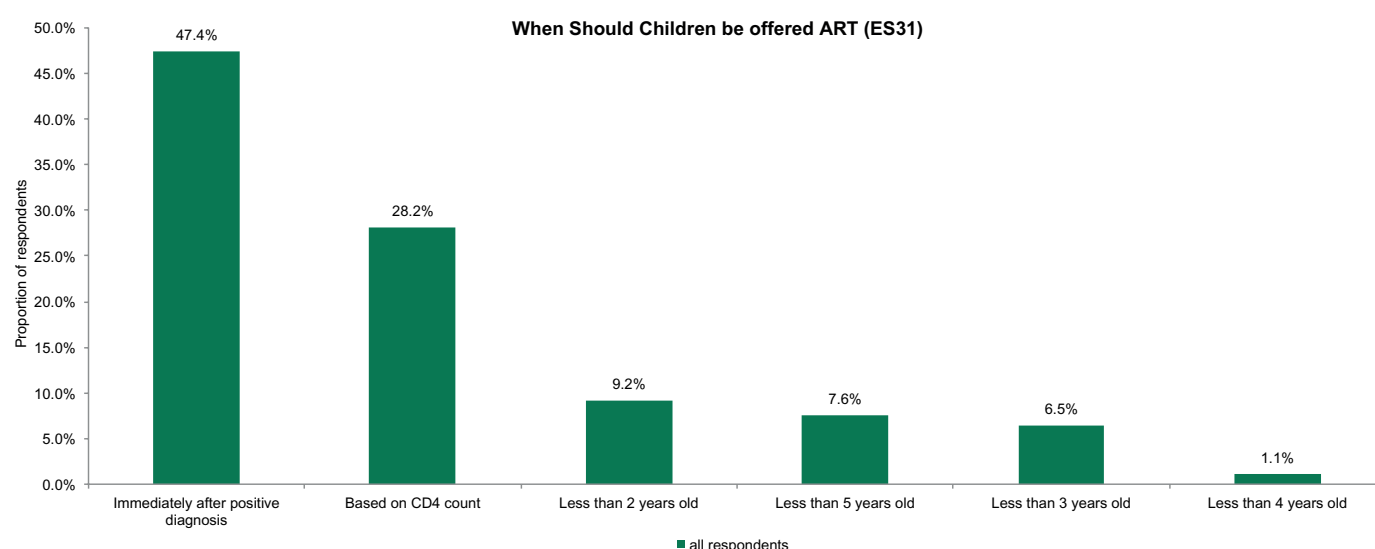


Figure 17. When should children be offered ART? (n=447)

Nearly half of community respondents agreed that children should initiate ART immediately after a positive HIV diagnosis (47.4% of all respondents). This is because earlier initiation may increase survival rates and improve retention in care; children who start ART with a higher CD4 cell count may respond better; the lack of access to CD4 testing would cease to be a barrier; and more children would be reached if the policy were to treat all young children. There were no statistical differences between people living with HIV and those not living with HIV in terms of their responses. However, regional difference emerged in the e-forum discussions, where respondents from African countries predominantly agreed that ART should be initiated regardless of CD4 cell count and viral load, while Russian e-forum respondents felt that a viral load or CD4 cell count criterion should be used.

Responses on specific age thresholds (i.e. two, three, four or five years old) were inconclusive, potentially due to the phrasing of the question<sup>32</sup> as well as a lack of community awareness about this clinical area. However, one e-forum contributor questioned whether recommending a certain age threshold but denying ART to children above that age was ethical. Therefore, the 2013 ARV Guidelines need to be sensitive to the range of views that exist in different contexts.

## What to start (children under three years of age)

### Key questions

- Should a non-nucleoside reverse transcriptase inhibitor (NNRTI)- or protease inhibitor-based first-line regimen be prescribed to children living with HIV under three years of age who start treatment and have not been exposed to PMTCT? (ES33, n=434; People living with HIV=245)
- How would you view a recommendation for LPV/r (protease inhibitor) as first-line treatment for all children living with HIV under three years of age regardless of previous NNRTI exposure? (ES34, n=434; People living with HIV =246)
- Should LPV/r-based ARVs or an alternative (e.g. NVP or a four-drug regimen) be the preferred regimen for children, and why? (EF)

Nearly half of the respondents (43.7%) indicated no preference on whether children under three years of age who had not been exposed to PMTCT should start a NNRTI- or protease inhibitor-based first-line regimen. Almost 38 % of the respondents preferred LPV/r; 17.6% preferred NVP. LPV/r was most preferred among respondents from low- and middle-income countries, while the “no preference” choice ranked highest in high-income countries. Overall, despite the prevalent theme of difficulties in storing and administering LPV/r syrup for infants, community respondents still preferred the regimen because of its perceived greater effectiveness.

## What to start (children over three years of age)

### Key questions

- Which first-line regimen would you prefer for children over three years of age living with HIV? (ES36, n=424)
- How would you view a recommendation to prescribe a TDF-based regimen for children over three years of age? (ES37, n=421)
- Should TDF or an alternative (e.g. zidovudine (AZT), d4T, abacavir (ABC), etc.) be used in children, and why? (EF)

Over one-third of all respondents preferred TDF-3TC-EFV as a first-line regimen for children over three years of age (36.6%). This may reflect current usage in respondents’ settings, and variations in knowledge and experience between types of country (e.g. respondents in low-income countries rated AZT-based regimens higher, which may reflect current usage in many of those countries). Respondents in low-income countries particularly preferred TDF because it is officially approved for children over two years of age, it can be given in a once-daily dose, and it does not need refrigeration.

32. It may have been more accurate to ask, “At what age limit should children who are diagnosed HIV positive not be offered ART?”

## Concerns regarding children living with HIV and ART

### Key questions

- What must change at the clinic, in communities or at home to increase the uptake of ART/retention by children living with HIV? (EF)

### Operational considerations

Official approval of proposed medication (e.g. TDF) for use in young children, once-daily dosing and ease of storage without refrigeration are important considerations for parents or caregivers, and can strongly affect their acceptance of and adherence to ART for their children.

Many community respondents highlighted side effects as an important consideration affecting acceptance of and adherence to ART by parents or caregivers. One said, *“Children’s bodies are still developing and frail and the side effects can be life threatening ... if treatment is initiated too early.”* Others stated that children should not have to take a risk that might harm them if it was not absolutely necessary. Respondents were also concerned about the effects of using ritonavir as a booster, and any use whatsoever of protease inhibitors with young children. Potential side effects were important enough for respondents to assert that use of viral load or CD4 cell count criteria for treatment initiation rather than age should be used.

Latin American respondents noted that, in addition to specialised care, children living with HIV “need psychological support because they do not know their HIV status and in some cases [are] blamed for the death of their parents where they have died from HIV/AIDS.” (Spanish e-forum)

Considering local context and resources, respondents identified distance from services as a key barrier to services. Bringing children’s ART services closer to the community, or expanding access to services through other means, without increasing the cost to community members was considered a priority by respondents. Additionally, stigmatising attitudes or lack of support that prevents children from accessing treatment can be mitigated by treatment literacy and awareness-raising programmes for parents, caregivers and healthcare providers.

### Rights, ethics, and equity considerations

Community respondents highlighted stigmatising attitudes and a lack of support from family members, communities or healthcare providers as barriers to children accessing treatment. Latin American participant highlighted that state-administered public foster homes in the region were not sensitised on care and treatment for children with HIV, and were responsible for a high level of discrimination against them.

Respondents offered various solutions, including employing national policies that support offering treatment literacy education, training and sensitisation, or other forms of education for parents, caregivers and healthcare providers (e.g. how to provide non-stigmatising care). Appropriate laws or policies at national level were suggested as a way to compel parents or caregivers to provide their children with access to treatment and care. A Ugandan respondent suggested, “do[ing] more to follow up at community level through ... community structures such as village health teams, volunteers and local councils”. (English e-forum)

### Community action and engagement implications

Respondents believe that community plays an important role in supporting treatment of children living with HIV, particularly in terms of follow-up. This may require community system strengthening and community mobilisation to ensure that appropriate structures exist and are properly equipped to fulfil this role. Communities, especially networks of people living with HIV, can offer appropriate training and awareness-raising to government health workers, community health workers, volunteers and caregivers, to ensure they are able to provide the care that children living with HIV require. Additionally, psychosocial support and care needed by children living with HIV could also be provided most effectively at community level.

### Key findings from the e-survey and e-forums regarding ART for children

- Respondents ranked “ART initiation for children immediately after positive HIV diagnosis” highest.
- The limited options of protease inhibitors for second-line ART and the higher risks of resistance and treatment failure with NVP regimens were important reasons for choosing a first-line regimen for children younger than three years of age.
- Official approval of proposed medication (e.g. TDF) for use in young children, once-daily dosing and ease of storage without refrigeration are important considerations for parents or caregivers, and can strongly affect their acceptance of and adherence to ART for their children. Despite concerns about storage and administration difficulties, respondents accepted LPV/r syrup because of its greater effectiveness.
- Respondents’ priorities are to bring children’s ART services closer to the community, or provide other support to community members so they can more easily access services without any increase in cost.
- Stigmatising attitudes or lack of support are barriers to children accessing treatment that can be mitigated by treatment literacy education, education and awareness-raising to parents, caregivers and healthcare providers.

### 3. Operational and service delivery aspects of HIV care and ART

In addition to the operational and service delivery issues raised in the clinical sections above, the e-survey addressed some specific issues that relate to topics in the 2013 ARV Guidelines, particularly on access to ART, retention in care, human resources, integration and decentralisation of services, and community systems.

#### A. Access to ARV treatment

##### Key questions

- Which of the following groups have the most difficulty accessing ARVs in your country? (ES58, n=362)
- Which of the following are the most challenging barriers for you to access ARVs? (ES59, n=330)
- What are the main barriers that must be addressed to improve HIV treatment access in your setting? (ES49, n=399)

Groups with most difficulty accessing ARVs (ES58)

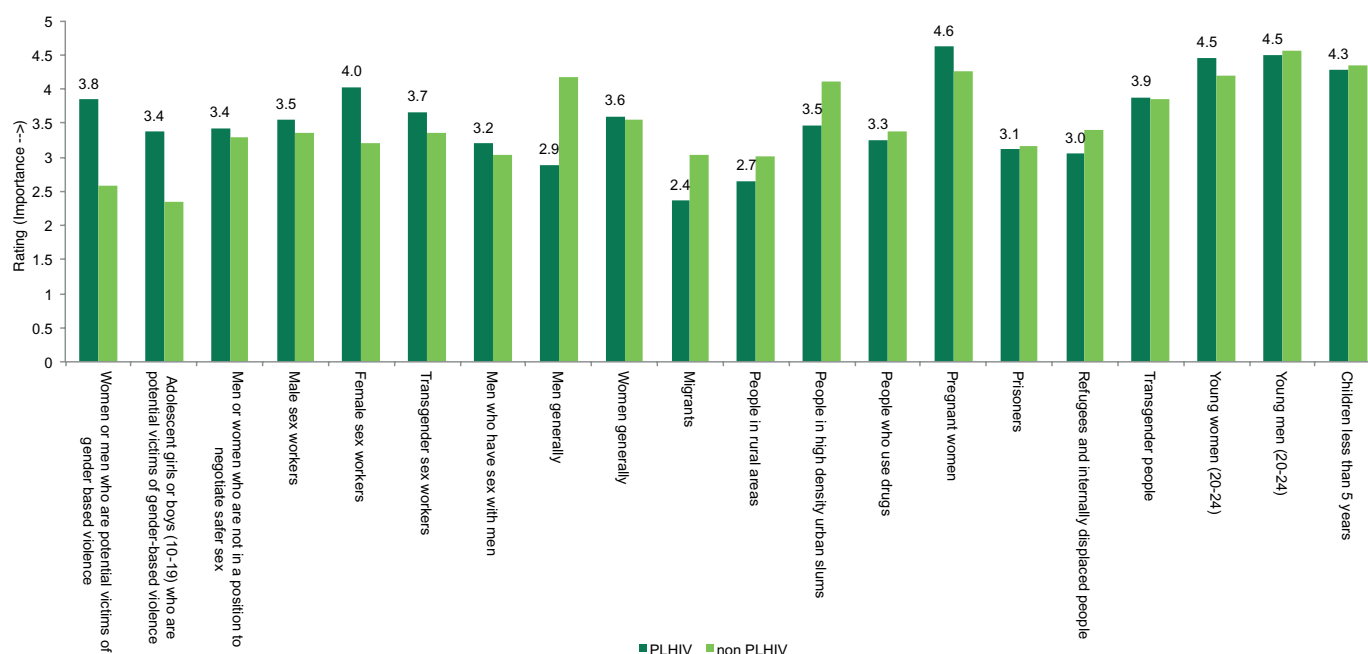


Figure 18. Groups with most difficulty accessing ARVs (n=362)

People living with HIV felt that pregnant women (4.46), young men (4.50) and young women (4.62) are among the groups with most difficulty accessing ARV in their context.<sup>33</sup> There were statistical differences in the responses between people living with HIV and those not living with HIV in relation to the following groups: women or men who are potential victims of gender-based violence (3.84 PLHIV; 2.59 non-PLHIV;  $p=0.01$ ); adolescent girls or boys (10–19) who are potential victims of gender-based violence (3.37 PLHIV; 2.34 non-PLHIV;  $p=0.03$ ); and young women (20–24) (4.46 PLHIV; 4.20 non-PLHIV;  $p=0.03$ ). However, further sub-analyses have noted that respondents' experiences and perceptions of, and assumptions about, other groups may bias their own choices, which limits the generalisability of these results.

33. The range was from 1 (least important) to 6 (most important).



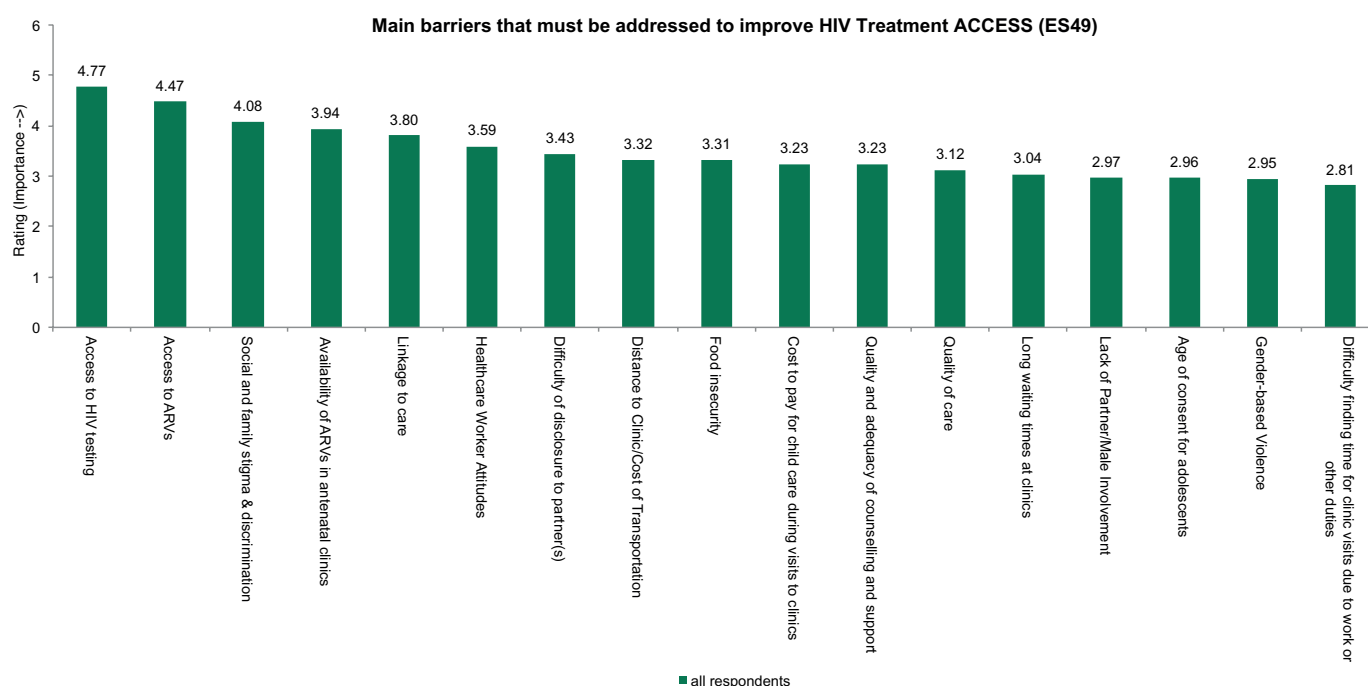


Figure 19. Main barriers that must be addressed to improve HIV treatment access (n=399)<sup>34</sup>

Community respondents identified access to HIV testing (4.77), access to ARVs (4.47) and social and family stigma and discrimination (4.08) among the most challenging barriers that must be addressed to improve HIV treatment access.

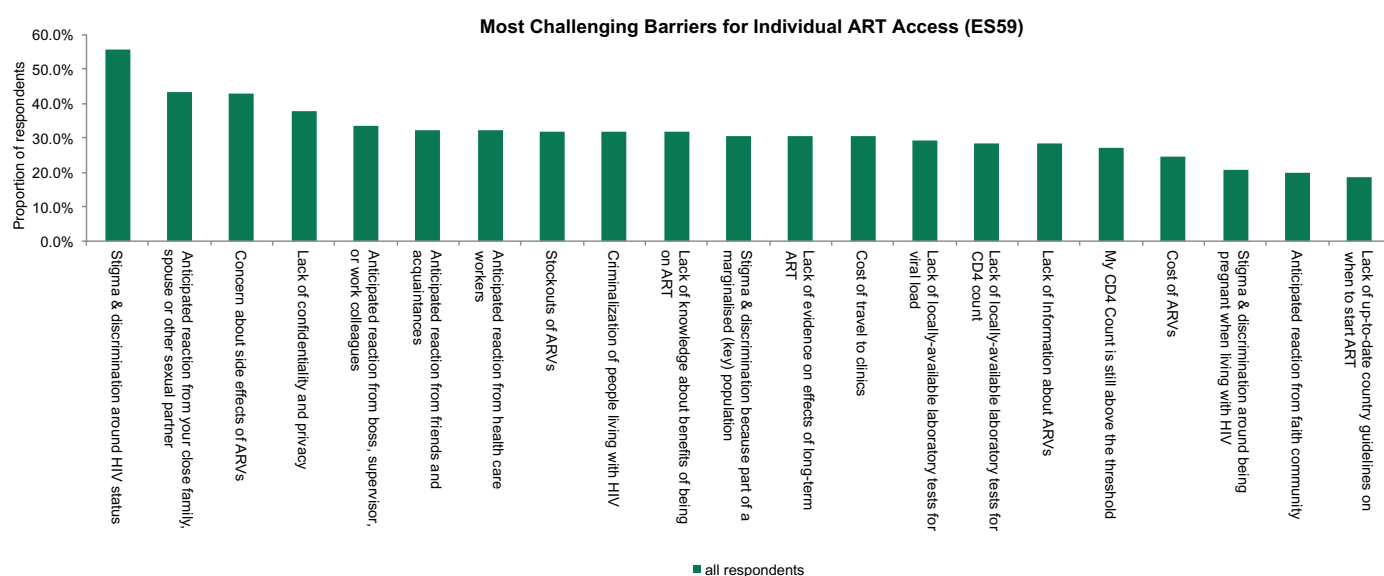


Figure 20. Most challenging barriers to individual ART access (n=330)

34. The range was from 1 (least important) to 6 (most important).

Community respondents identified the following as the most challenging barriers to individuals accessing ART: stigma and discrimination around HIV status (55.8%); anticipated reactions from close family, spouse or other sexual partner (43.3%); concern about side effects of ARVs (43.0%); and lack of confidentiality and privacy (37.9%). Respondents from key populations prioritised these answers slightly differently. For example, respondents who were young people (20–24), adolescents, people who inject drugs, sex workers or migrants felt that a lack of updated ART guidelines was more of a challenge than non-key population respondents. These differences may relate to the lack of attention to key populations in older guidelines, and the perception that inclusion of guidelines specific to key populations may lead to a greater chance of being able to realise their rights to HIV care and ART.

## B. Retention in care, treatment literacy and adherence

### Key questions

- What are the main barriers that must be addressed to improve retention in care in your setting? (ES50, n=373)
- What are the main barriers that must be addressed to improve HIV treatment adherence in your setting? (ES51, n=366)
- The following approaches are good ways to promote adherence to ART. (ES52, n=381)
- Where do you think is the best setting for treatment education? (ES62, n=370)

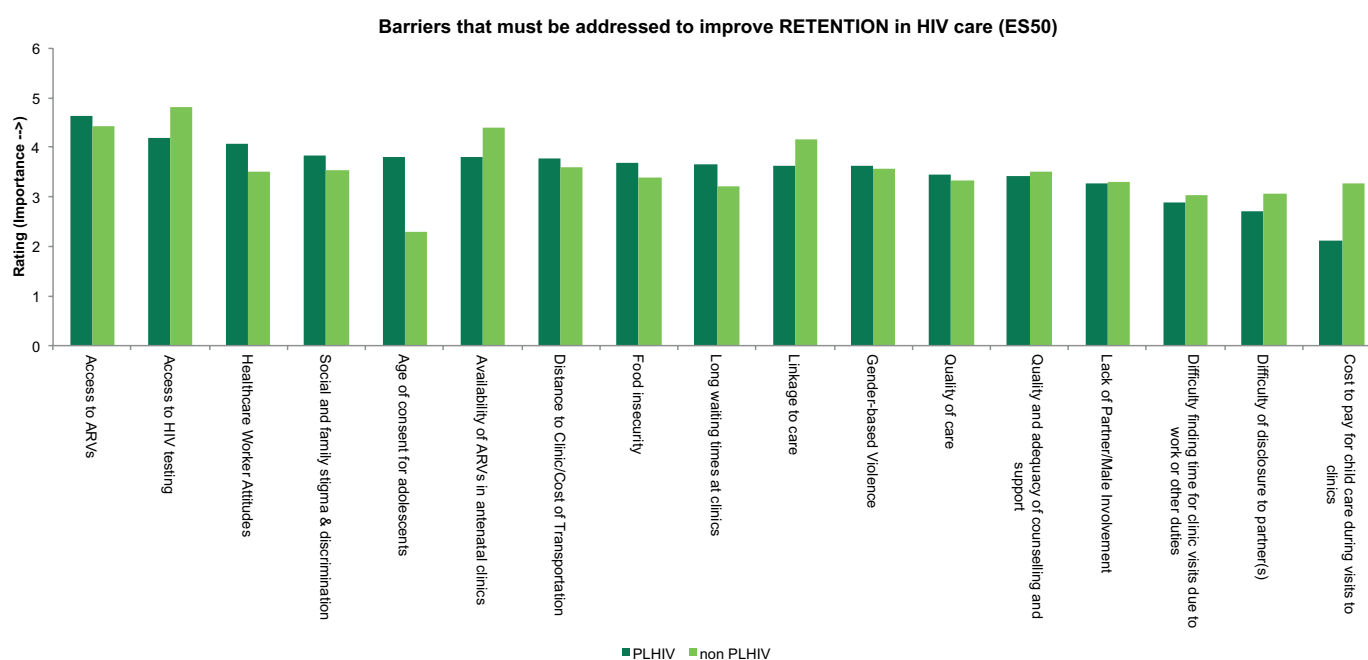


Figure 21. Barriers that must be addressed to improve retention in HIV care (n=373)<sup>35</sup>

Community respondents again identified access to ARVs (4.63 PLHIV) and HIV testing (4.2 PLHIV) as among the most challenging barriers that must be addressed to improve retention in HIV care. There were some statistical differences ( $p < 0.05$ ) between people living with HIV and those not living with HIV. For example, people living with HIV identified healthcare provider attitudes (4.06 versus 3.51) and age of consent for adolescents (3.80 versus 2.29) as more challenging barriers, whereas those not living with HIV regarded access to HIV testing (4.8), linkage to care (4.17) and availability of ARVs in antenatal clinics (4.39) as more important. There were also differences across country income levels (e.g. access to HIV testing was rated more highly by respondents in middle- and low-income countries). This disparity provides another reminder that the barriers actually identified by people living with HIV themselves should be prioritised to improve their retention in care.

35. The range was from 1 (least important) to 6 (most important).

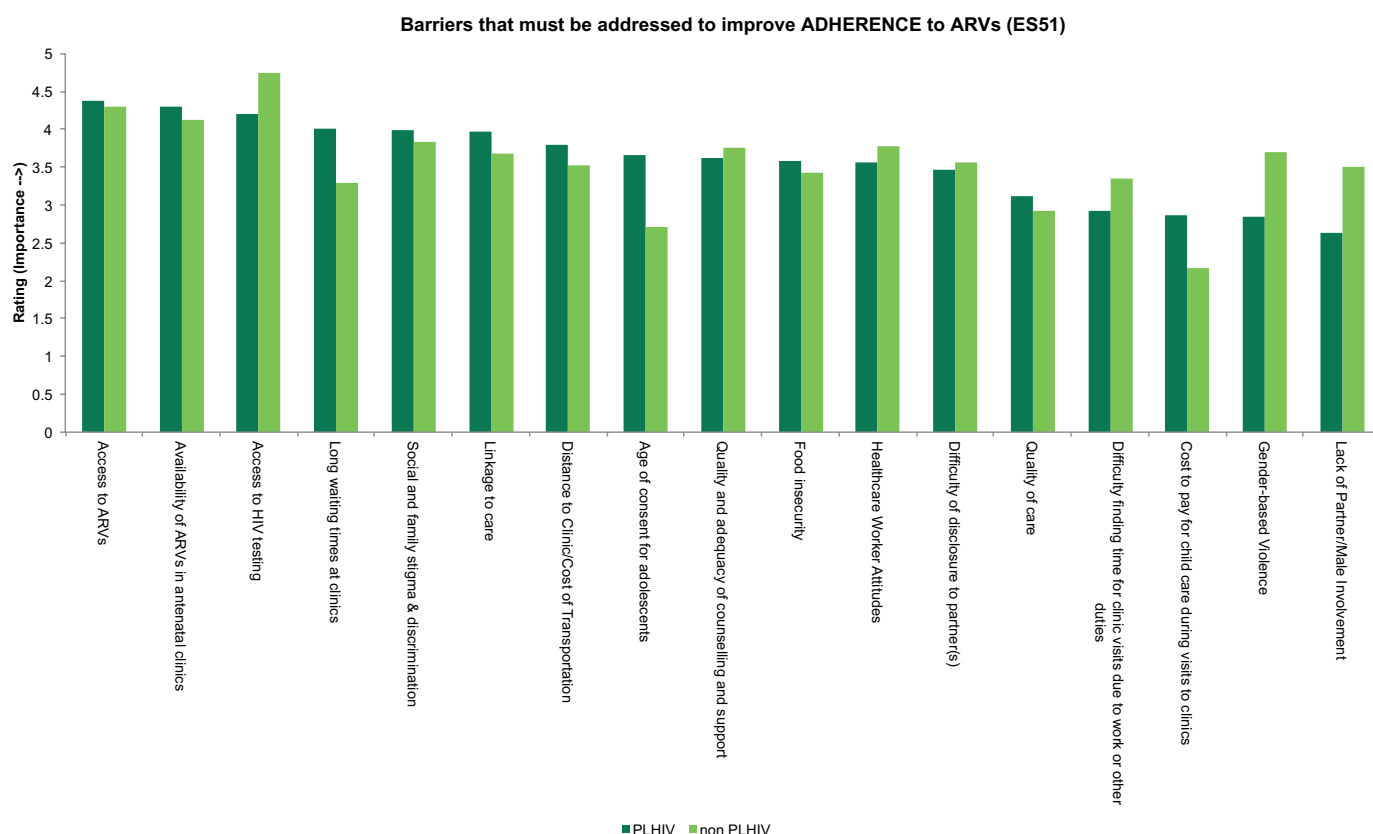
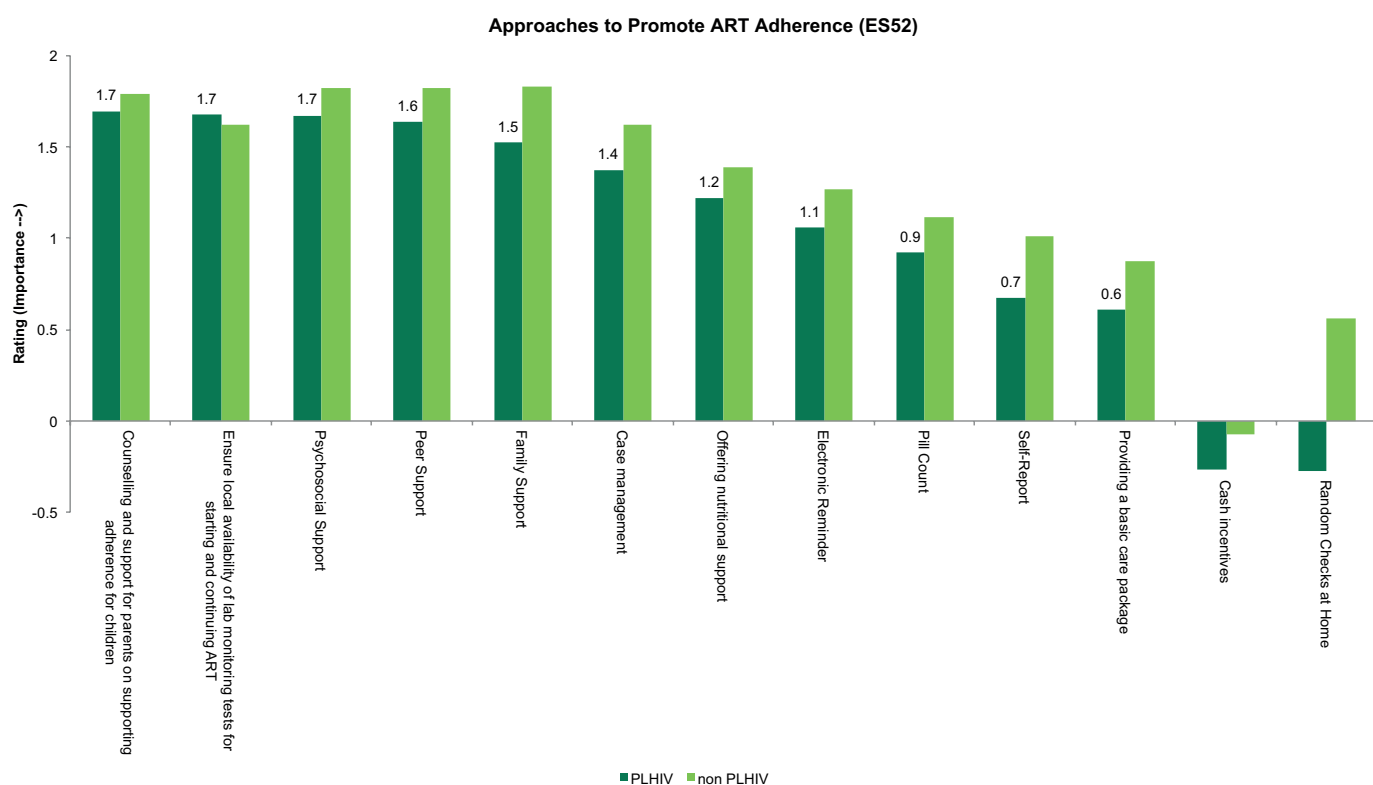


Figure 22. Barriers that must be addressed to improve adherence to ARVs (n=366)<sup>36</sup>

Concerning barriers that must be addressed to improve HIV treatment adherence, community respondents once again identified access to ARVs (4.39 PLHIV), availability of ARVs in in antenatal clinics (4.31 PLHIV) and access to HIV testing (4.20 PLHIV) as among the most challenging barriers. Women more frequently than men identified age of consent for adolescents, lack of male involvement and costs of childcare, while men were more concerned about long waiting times at clinics.



36. The range was from 1 (least important) to 6 (most important).

Figure 23. Approaches to promoting ART adherence (n=381)<sup>37</sup>

Community respondents identified counselling and support for parents or caregivers on supporting adherence for children (1.79 among people living with HIV), ensuring local availability of laboratory monitoring tests for starting and continuing ART (1.68 among people living with HIV), psychosocial support (1.67 among people living with HIV) and peer support (1.64 among people living with HIV) as among the preferred approaches to promote adherence to ART. Responses from people living with HIV on family support (1.52 among people living with HIV; 1.83 among people not living with HIV;  $p=0.01$ ) and random checks at home (-0.27 among people living with HIV, meaning people living with HIV disagreed with this approach; 0.56 among people not living with HIV  $\leq 0.01$ ) were statistical different from responses from those from people who were not living with HIV. Pill counting and self-reporting as techniques to support adherence were more favoured in low-income countries. This is possibly because these approaches are favoured where pharmacy systems are less well equipped to track ARV usage through dispensing records. The approaches prioritised by people living with HIV respondents emphasise the importance of a comprehensive package of interventions and the importance of human support along with more technical and clinical interventions.

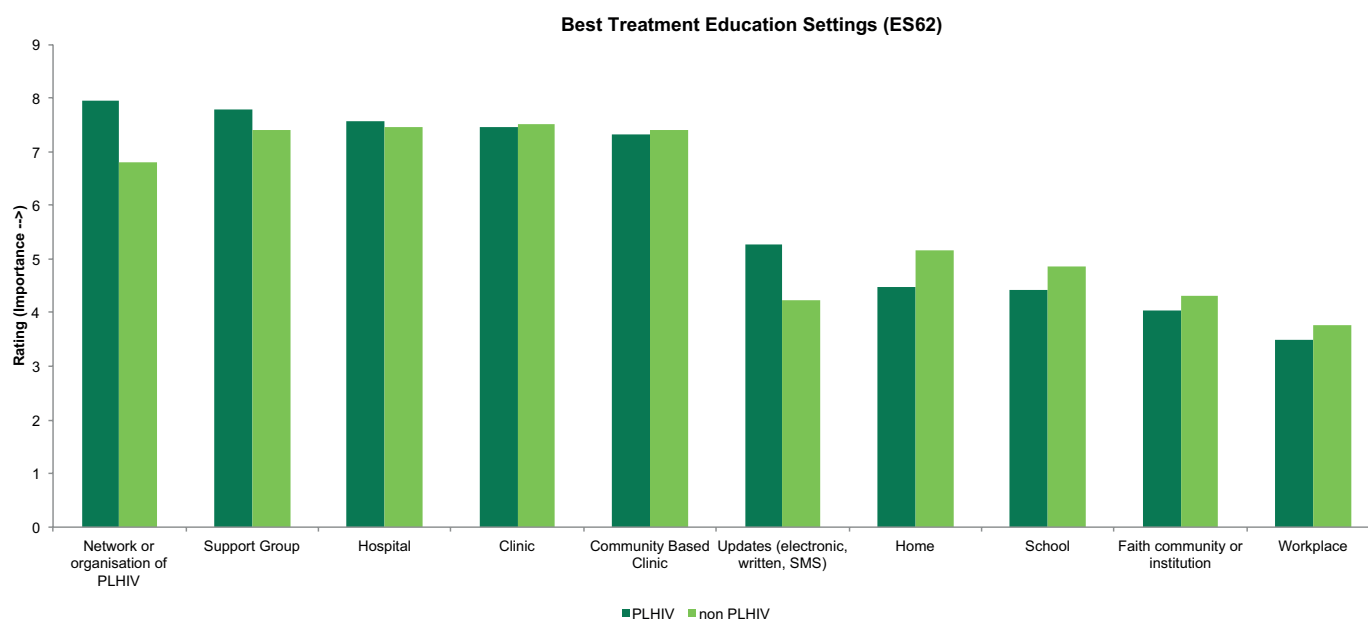


Figure 24. Best treatment education settings (n=370)<sup>38</sup>

While all settings were considered important, people not living with HIV identified networks of people not living with HIV, support groups, hospitals and clinics as among the best settings for treatment education. Specific rating were 7.79 compared to 7.4 among people not living with HIV; for support groups ( $p=0.02$ ) and 7.97 compared to 6.80 among people not living with HIV for networks ( $p<0.01$ ), reflecting a preference for peer support among people living with HIV. In addition, people living with HIV strongly preferred updates compared to people not living with HIV (5.28 versus 4.22;  $p<0.01$ ).

## C. Task-shifting and decentralisation

### Key questions

- If they receive adequate training and regular supervision and updating, should nurses be allowed to provide HIV care and treatment services to people living with HIV who are stable and do not require a doctor's consultation? (ES63, n=365)
- If they receive adequate training and regular supervision and updating, should community health workers be allowed to provide HIV care and treatment services to people living with HIV who are stable and do not require a doctor's or nurse's consultation? (ES64, n=367)
- What are the key barriers to task-shifting or sharing in your context? (ES67, n=346)

37. The range was from 2 (strongly agree) to -2 (strongly disagree).

38. The range was from 1 (least important) to 11 (most important).

## Box 2. Terminology<sup>39</sup>

- **Task-shifting** involves the rational redistribution of tasks among healthcare provider teams. Specific tasks are moved, where appropriate, from highly qualified healthcare providers to those with shorter training and fewer qualifications in order to make more efficient use of the available human resources for health.
- **Task-sharing** is another term used to emphasise sharing of clinical tasks among teams of different cadres of health workers. Both emphasise the need for training and continued educational support of all cadres of health workers in order for them to undertake the tasks they are to perform.

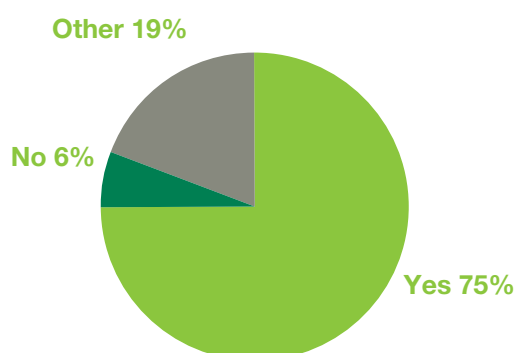


Figure 25. Task-shifting/sharing to nurses (n=365)

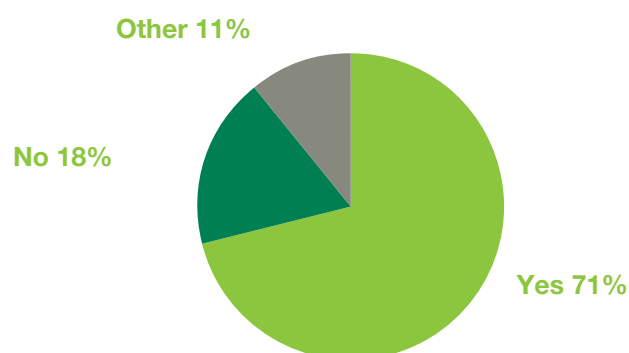


Figure 26. Task-shifting/sharing to community health workers (n=367)

Community respondents expressed that if nurses and community health workers receive adequate training, regular supervision and updating, they should be allowed to provide HIV care and treatment services to people living with HIV who are stable and do not require a doctor's consultation. An e-forum respondent added, "Research in the US suggests that advance practice nurses who specialise in HIV actually have as good as or better patient outcomes than general practice physicians."

39. WHO, UNAIDS, PEPFAR (2008), Task shifting: rational redistribution of tasks among health workforce teams: global recommendations and guidelines. Available at: <http://www.who.int/healthsystems/TTR-TaskShifting.pdf> (accessed 11 June 2013).

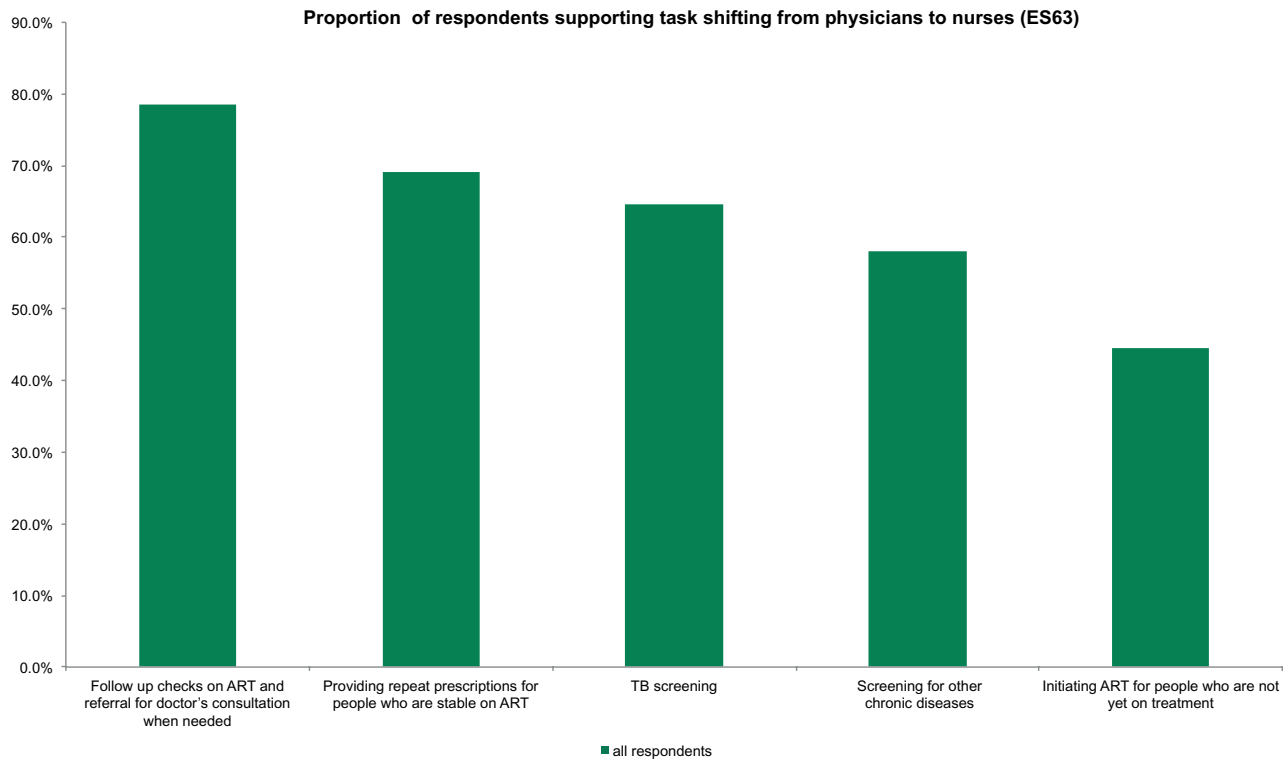


Figure 27a. Suitability for task-shifting/sharing to Nurses (n=346)

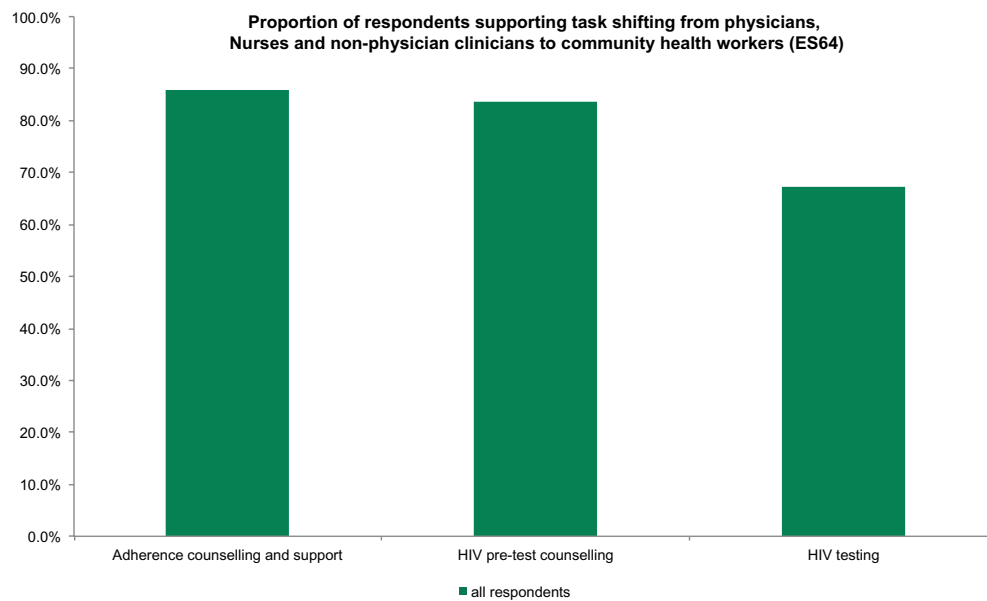


Figure 27b. Suitability for task-shifting/sharing to CHWs (n=341)

Although the majority of respondents supported task-shifting/sharing to nurses and community health workers, there were differences regarding which specific tasks should be shifted. For instance, while 65% of respondents supported enabling nurses to renew ART prescriptions, only 43% agreed with enabling nurses to initiate ART.

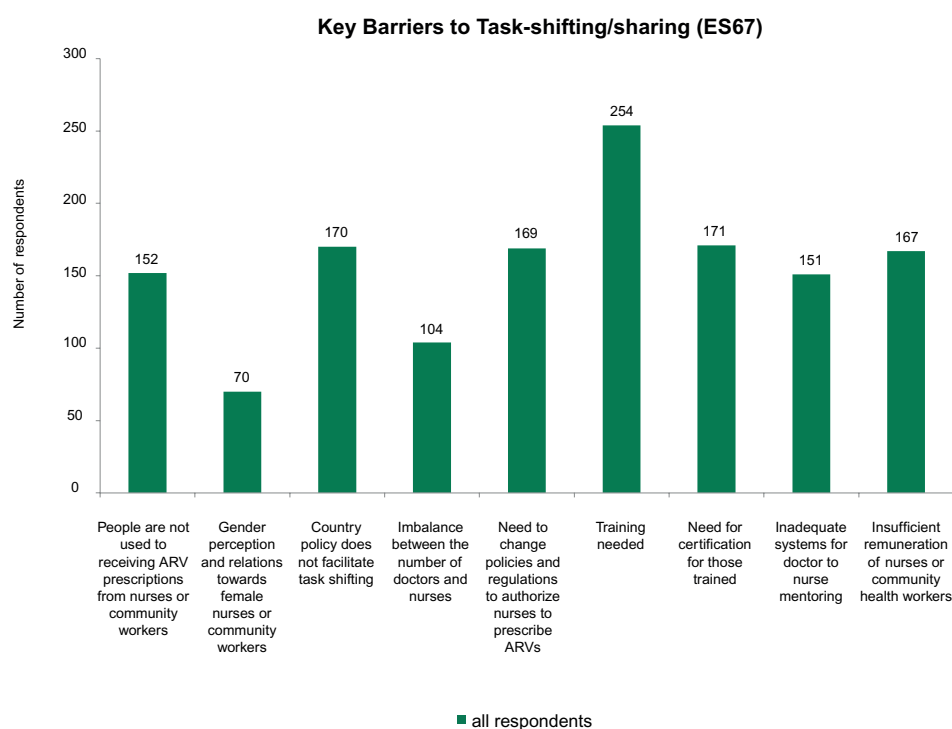


Figure 28. Key barriers to task-shifting/sharing (n=346)

However, community respondents identified training, certification, national policies and remuneration as among the most challenging barriers to task-shifting/sharing.

## D. Service integration

### Key questions

- ART should be integrated into the following services. Do you agree? (ES68, n=361)
- The following services should be integrated into ART services. Do you agree with this? (ES69, n=361)

Community respondents strongly agreed that ART services should be integrated into TB, hepatitis B or hepatitis C, SRH, maternal and child health, and harm reduction services, and vice versa. There were no statistical differences based on HIV status, gender, country income status, or whether respondents self identified as key populations or not. One e-forum contributor pointed out that in their location, Cote d'Ivoire, there was currently no policy or mechanism enabling the integration of HIV and SRH services. This lack of integrated services was identified as a barrier to accessing PMTCT care.

## E. Role of communities (in HIV care and ART delivery)

### Key questions

- How should communities and civil society be involved in decision-making regarding ARV at the country level? (EF)
- How can the process of decision-making regarding the use of ARVs be made more inclusive, fair and transparent at the country level? (EF)
- What should countries consider when deciding how to use ARVs for prevention and/or treatment? Why? (EF)



Community respondents specified that in order to underline the importance of the right to health services for all, the 2013 ARV Guidelines should explicitly address key populations' needs. Guidelines are often compromised because healthcare providers and patients have little or no knowledge of gender issues, key population issues, human rights, laws or policies that can support or hinder access. Community respondents suggested that the 2013 ARV Guidelines could articulate the requirement for sensitisation and the steps necessary to achieve this. All e-forum discussions specifically noted that any domestication of the 2013 ARV Guidelines should take into account the specificities of each context to support effective implementation.

Community respondents discussed the importance of community systems linkages with health systems and of support for ART adherence, stigma reduction and advocacy. Across discussions, communities were seen as critical partners for civil society and government in advocating for the elimination of stigma and discrimination; demanding and supporting inclusive, fair and transparent ART programmes; holding leaders to account; and supporting adherence to treatment. Community respondents emphasised the importance of involving communities at all stages of developing and implementing the 2013 ARV Guidelines. They suggested further consultation at country or regional levels on issues relating to changes in the national guidelines and problems with national protocols, standards and policies. Meetings between community representatives, WHO and national ministry of health staff should be held to ensure that the voices of communities were heard and considered legitimate by governments. Additionally, community respondents recommended creating a group of community representatives to evaluate changes and introduce the 2013 ARV Guidelines.

Community respondents in this consultation have clearly identified community mobilisation, empowerment and sensitisation as requirements to successfully supporting access to services for people living with HIV and other key populations, and addressing human rights issues. Echoing the results of the Harare and Bangkok community consultations, community respondents in this consultation highlighted the many roles communities are uniquely positioned to play in service delivery, scale-up of interventions, operational research and evaluation, and advocacy at local, national and regional levels to increase the effectiveness of efforts to provide access to HIV care and ART for all who need it (see Table 3). These should be included in any future consideration of the role of communities in this area.

**Table 3. HIV services and activities that community-based providers are uniquely placed to deliver<sup>40</sup>**

Treatment	Prevention	Advocacy
<ul style="list-style-type: none"> <li>• Adherence support</li> <li>• Testing and counselling</li> <li>• Treatment literacy</li> <li>• Linkage to care/support services</li> <li>• Linkage to harm reduction services</li> <li>• Management of health and psychosocial needs following testing</li> <li>• Disclosure support</li> <li>• Treatment delivery (a treatment extension role for community organisations)</li> <li>• Case management</li> <li>• Nutritional support</li> </ul>	<ul style="list-style-type: none"> <li>• PMTCT</li> <li>• Harm reduction services (syringe exchange, opioid substitution therapy, etc.)</li> <li>• Sexuality education</li> <li>• SRH and rights awareness</li> <li>• Condom distribution</li> <li>• PrEP education</li> <li>• Education on TB infection control</li> <li>• Contact tracing/partner notification support</li> <li>• Client negotiation, collectivisation, peer outreach skills for sex workers</li> <li>• Promotion of male circumcision</li> <li>• Post-exposure prophylaxis for sexual assault survivors</li> </ul>	<ul style="list-style-type: none"> <li>• Monitoring and accountability (health systems, government responses, rights abuses, quality of services)</li> <li>• Quality assurance of health services</li> <li>• Anti-stigma, anti-discrimination and decriminalisation (legal support, law reform, lobbying)</li> <li>• Policy analyses around access to and development of essential medicines</li> <li>• Ensuring meaningful involvement of people living with HIV in policy and programme development</li> </ul>

40. Adapted from the following meeting report: Optimising HIV Treatment Access and Retention in Care: Linking Community Level Interventions with Healthcare Delivery Systems A Treatment 2.0 Initiative Organised by the Asian Pacific Network of People Living with HIV/AIDS and Pangaea Global AIDS Foundation in Partnership with WHO and UNAIDS. September 18 – 20, 2012. Bangkok Thailand. Page 6. Available at <http://icssupport.org/wp-content/uploads/2013/05/Bangkok-service-delivery-meeting-final-report.pdf> last accessed August 13, 2013

## Key findings from the e-survey and e-forums regarding operational and service delivery aspects of ART and HIV care

- Addressing barriers to HIV testing access, ARVs access, and stigma and discrimination are essential to improving HIV treatment access, retention in care and adherence to ART.
- A comprehensive package of interventions, including human support (i.e. counselling support, psychosocial support, peer support, etc.) along with more technical and clinical interventions (e.g. local availability of laboratory monitoring for starting and continuing ART), is necessary to promote ART adherence.
- Networks or organisations of people living with HIV, support groups, hospitals and clinics are among the best settings for treatment education.
- Communities support task-shifting/sharing to and with nurses and community health workers as an overarching strategy to increase access to HIV care, but differentiate between the tasks to shift or share. Policies and regulatory frameworks to facilitate sustainable task-shifting/sharing and remuneration at country level are urgently needed. Such review of policies and regulatory frameworks should promote the involvement of communities, including people living with HIV, at a country level. A more in-depth and representative assessment of the perception of communities on task-shifting/sharing is needed to build on these findings.
- Communities support integration of ART and other services.
- Key populations need to be explicitly addressed in the 2013 ARV Guidelines to underline the importance of the right to health services for all and the need to appropriately design services according to the national context of the epidemic and the specific communities affected. This would ensure that national policymakers and service providers are made fully aware of the goal to appropriately address the needs of all key populations for equitable treatment and prevention information, despite the fact that some nations criminalise these groups.
- Communities are uniquely positioned to play various roles in service delivery, scale-up of interventions, operational research and evaluation, and advocacy at local, national and regional levels to increase the effectiveness of efforts to provide access to HIV care and ART for all who need it.

# 4. Programmatic decision-making

## Key questions

- 1. How should communities and civil society be involved in decision-making regarding ARV at the country level? (EF)
- 2. How can the process of decision-making regarding the use of ARVs be made more inclusive, fair and transparent at the country level? (EF)
- 3. What should countries consider when deciding how to use ARVs for prevention and/or treatment? Why? (EF)
- 4. What should countries consider relating to the human rights of people living with HIV when deciding how to use ARVs for prevention and treatment? (EF)
- 5. If you were a national programme manager who needed to choose between providing some but not all the health services your country needs, what factors do you think are most important in helping you prioritise? (ES70, n=344)

## A. Key factors for prioritising service provision

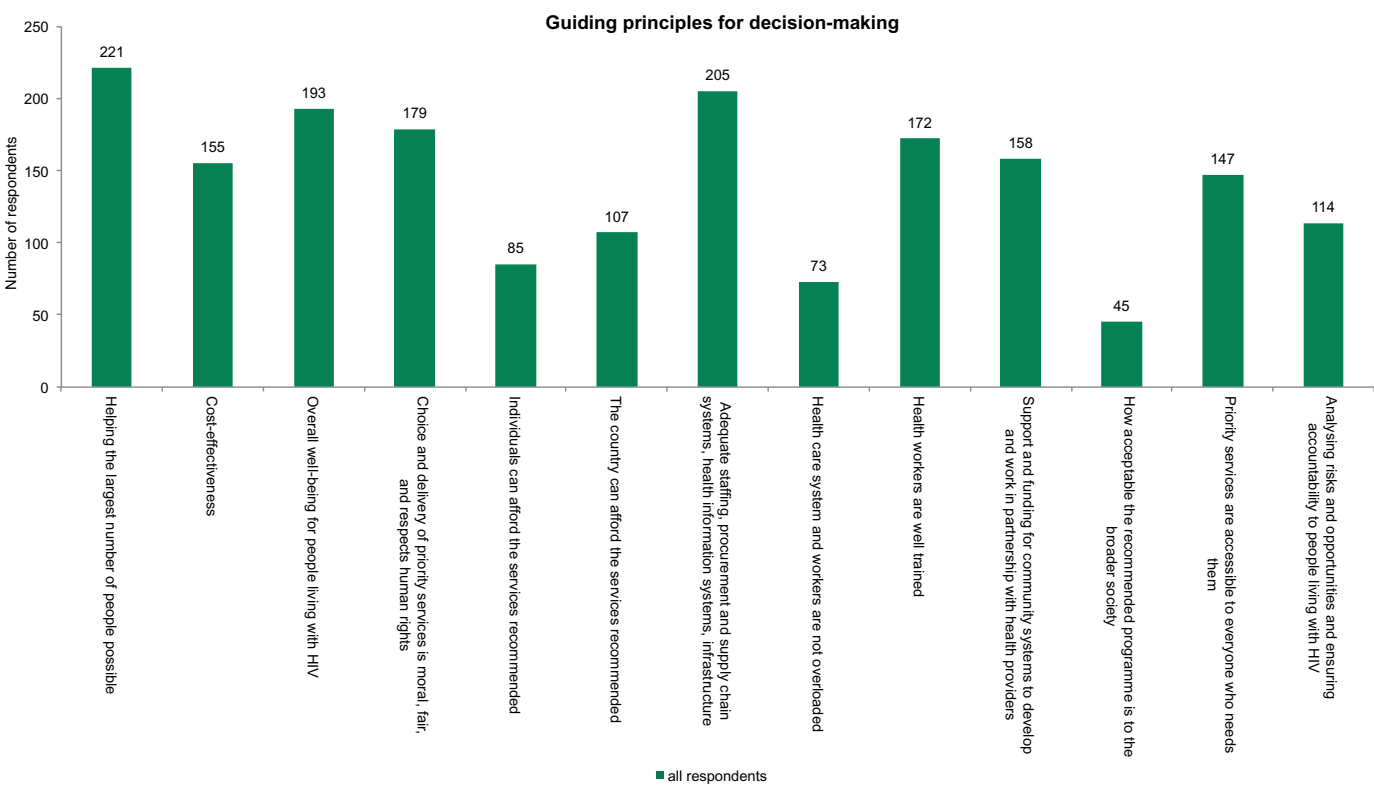


Figure 29. Important factors for programme managers to consider (ES70, n=344)

Community respondents ranked factors to be prioritised by national programme managers who need to choose between providing some but not all the health services a country needs. They prioritised approaches that provide overall public health benefits (63%), a functioning health system (59%) and safeguarding the overall wellbeing of people living with HIV (55%). However, community respondents indicated that programmes must also support the protection of rights, ethics and equity (51%), training of healthcare providers (49%), and funding of community systems (45%). There were no statistical differences based on self-identified HIV status or country income status. Overall, the responses did not indicate major differences between the 13 principles in the list.

Community respondents also raised various *key programmatic considerations and recommendations*, presented throughout this report, but highlighted here for ease of reference.

## **HIV testing and counselling**

1. Involve people living with HIV and other key populations in designing and scaling up existing HTC service delivery models in different settings to reflect the challenges faced by people living with HIV and to ensure acceptability and effectiveness.

## **Early initiation of treatment**

1. Programmes employing TasP approaches should acknowledge that the primary benefit of treatment is for the individual and that the secondary benefit is for prevention.
2. Early initiation of ARVs (i.e. any TasP approaches) should always be paired with and not replace behavioural and community interventions.
3. Informed choice is critical to a rights-based approach to TasP. Personal readiness continues to be an important aspect of treatment initiation. Individual patients are best placed to make a decision about when to initiate ART, once adequately informed. Doctors can facilitate choices by offering recommendations and motivating patients, so that patients as individuals can make decisions about when to begin treatment. Public education about TasP (including in schools) is also needed.
4. Early initiation of treatment and roll out of other new interventions (e.g. PrEP, viral load monitoring) require consensus at all levels (national, district and local) and across all sectors on communication and messaging around these changes and their implications, based on proven principles of communication, including robust field-testing. They also require in-depth, appropriate consultations with the communities who will be given the option to use these technologies.

## **ART for people with co-infections**

People living with HIV diagnosed with TB, hepatitis B or hepatitis C need a combination approach with a package of services and support. No single intervention alone will be effective.

## **Transitioning from older to newer ARVs**

1. The majority of people living with HIV believe d4T should be phased out and only used in exceptional circumstances (e.g. only for salvage therapy when no other treatment options exist). National strategies and grant applications should include fully costed plans to switch from d4T to newer ARVs.

## **Pre-exposure prophylaxis**

1. Specific groups of people should have the option to use PrEP, particularly those unable to negotiate safer sex, MSM and potential victims of gender-based violence.
2. Reservations about diverting scarce resources to PrEP where universal access to ART for those who are eligible has still not been achieved, poor adherence to PrEP regimens and potential toxicities cause community respondents to question the promises of PrEP.
3. The roll out of PrEP requires in-depth, appropriate consultations with the communities who will be given the option to use these technologies to ensure its acceptability and effectiveness.

## **Starting pregnant women living with HIV on lifelong ART (Option B+)**

1. For Option B+ to be successful, the following treatment/adherence issues must be addressed:
  - a. Need to guarantee access to uninterrupted, first-line and second-line ART.
  - b. Need to increase ease of accessing ARVs.
  - c. Ensure that CD4 cell count testing or a suitable monitoring alternative is available.
2. For Option B+ to be successful, the following service quality/capacity issues must be addressed:
  - a. Need to increase linkage between SRH and HIV services (including ART clinics).
  - b. Need to invest in programmes that increase retention of mother and child in postnatal ART care.
  - c. Need to invest in the capacity of community-led services and health facility-based services.
3. For Option B+ to be successful, the following social/legal issues must be addressed:
  - a. Need to invest in interventions that address stigma and discrimination by healthcare providers, families and communities.
  - b. Need to invest in interventions that address gender-based violence (relating directly to HIV status, treatment, etc.).
  - c. Need to address stigma and discrimination against pregnancy outside of marriage.
  - d. Need to address the criminalisation of HIV exposure/transmission.
  - e. Need to prevent forced or coerced sterilisation.
  - f. Need to be cognisant of the ethical issues that may arise from putting pregnant women on treatment while leaving out other people who may be in need of ARVs.

## **ART for children**

1. Official approval of proposed medication (e.g. TDF) for use in young children, once-daily dosing and ease of storage without refrigeration are important considerations for parents or caregivers, and can strongly affect their acceptance of and adherence to ART for their children. Despite concerns about storage and administration difficulties, respondents accepted LPV/r syrup because of its greater effectiveness.
2. Bringing children's ART services closer to the community or providing other support to community members so they can more easily access services without increasing the costs to them is considered a priority by respondents.
3. Stigmatising attitudes or lack of support are barriers to children accessing treatment that can be mitigated by treatment literacy education, education and awareness-raising to parents, care givers and healthcare providers.

## **Operational and service delivery aspects of ART and HIV care**

1. Addressing barriers to accessing HIV testing and ARVs, and addressing stigma and discrimination, are essential to improving HIV treatment access, retention in care and adherence to ART.
2. A comprehensive package of interventions, including human support (i.e. counselling, psychosocial and peer support, etc.), along with more technical and clinical interventions (e.g. local availability of laboratory monitoring for starting and continuing ART), is necessary to promote ART adherence.
3. Explicit policies that endorse and mandate nurses and community health workers to perform expanded roles in service delivery are needed.
4. Key populations need to be explicitly addressed in order to ensure that national policymakers and service providers are made fully aware of the goal to address appropriately the needs of all key populations for equitable treatment and prevention information, despite the fact that some nations criminalise these groups.

## **Increased integration and decentralisation of services**

1. Programme managers should develop policies and regulatory frameworks to support integration of HIV and other services, and decentralisation of services; for instance, to reduce the barriers associated with travelling long distances to centralised services, and bring services closer to the community.
2. Integration of services for key populations in particular must be coordinated in a sensitive manner so that services remain available and acceptable to communities, health outcomes are improved, and stigma and discrimination are not exacerbated.

## **Human rights, legal and ethical issues**

1. The right to health is a human right for all. It is critically important to know your epidemic and to target appropriately those who are the most affected within the overall HIV response.
2. People living with HIV and other key populations need to feel safe and comfortable in order to access the services they need. Prioritise interventions that inform both service providers and patients on the critical role of human rights and gender in optimising treatment and care.
3. While interventions such as early initiation of ART (TasP) are valuable, they should be accompanied by a clear understanding of the human rights of all those involved. Human rights assessments and monitoring are critical tools in ensuring human rights protection and personal choice.
4. The Harare meeting report (March 2012) stresses, "There is potential for human rights violations at every stage of the HIV treatment cascade. Efforts to create enabling human rights environments for people living with HIV and those most affected must be central to the response to HIV and the Treatment Optimization Framework. An enabling environment includes: the repeal and non-enforcement of punitive laws such as those that criminalize consensual sex between men, sex work, and drug use; the repeal of HIV-specific laws that criminalize transmission of HIV (even without intent); the enactment and enforcement of legislation that strengthens a rights-based approach to HIV, including anti-discrimination laws; access to justice for key populations." The same report stresses that "rights-based service delivery interventions need to be better defined, studied, and implemented"; "rights-based approaches must be part of programme development as well as part of the development of service delivery approaches"; and Know Your Rights Campaigns, which "empower those affected by HIV to understand their rights in the context of the scale-up of testing and treatment, are critical."
5. Laws that criminalise HIV exposure, transmission, and non-disclosure and certain behaviours of key populations inhibit ART access. ART programmes can only be effective in legally conducive environments. Legal reform must accompany any changes to ART programmes.  
"As a gay man living with HIV since at least 1989, I bring awareness that some 76 countries still criminalize homosexuality. From direct contact through various PLHIV forums, I can tell you it is certainly a very distressful life for many MSM living with HIV who live in these nations. Some are still subject to assault and rape, torture and death for loving a person of the same sex! These are clearly appalling disincentives to being sufficiently open about being an MSM for many MSM to even seek diagnosis or treatment for HIV!"  
(e-forum respondent, English discussion)
6. Rights and treatment literacy are needed to sensitise health service providers and patients on gender issues, human rights, and laws or policies that can support or hinder access. Lack of awareness or knowledge often compromises implementation of guidelines.

## **Structural drivers and social determinants of health**

1. ART programmes do not operate in a vacuum. Social and structural drivers around health, including vulnerability to HIV, limit an individual's and a community's options, and can reduce the likelihood of treatment access, adherence and retention in care. While programmatic guidance cannot provide recommendations around all structural drivers, it must urge consideration of the guidelines in the context of the broader factors through cross-sectoral dialogue. Such structural drivers include, but are not limited to, stigma, gender-based violence, gender inequity, homophobia, poverty and food security.

## **Role of communities in developing and implementing new guidelines**

1. Communities are critical partners for civil society and government in advocating for the elimination of stigma and discrimination, demanding and supporting inclusive, fair and transparent ART programmes, and holding leaders to account.  
“The decision-making regarding the use of ARVs can only be made more inclusive, fair and transparent at the country level by involving, engaging and consulting stakeholders at all levels. The community of both those living with HIV and those who are negative should all be part of the stakeholders.” (e-forum respondent, English discussion)
2. Investment in community system strengthening is essential to ensure that structures exist and are properly equipped to support referral and access to care, treatment, retention and adherence, and thus also contribute to health systems strengthening.
3. Communities are uniquely positioned to play various roles in service delivery, scale up of interventions, operational research and evaluation, and advocacy at local, national and regional levels to increase the effectiveness of efforts to provide access to HIV care and ART for all who need it.
4. Networks or organisations of people living with HIV, support groups, hospitals and clinics are among the best settings for treatment education.
5. Explore mechanisms/good practices for involving key populations in developing new national guidelines.  
“Communities should pro-actively support those that are HIV positive and ensure they are linked to care and treatment ... they should be consulted on what they want governments to do for them regarding ART ... [they should be] empowered to keep their leaders accountable and support the ART programmes.” (e-forum respondent from Uganda, English discussion)
6. Involve communities in the implementation and evaluation of new guidelines, such as through community advisory boards and through engagement at a national level in national coordinating mechanisms.

**Annex 1: E-Survey Questions (online at [www.aidsalliance.org](http://www.aidsalliance.org))**

**Annex 2: E-Forum Questions (online at [www.aidsalliance.org](http://www.aidsalliance.org))**

**Annex 3: Number of respondents from each country**

Algeria (1), Anguilla (1), Argentina (7), Armenia (1), Australia (14), Austria (1), Bangladesh (3), Barbados (4), Belgium (5), Belize (1), Benin, People's Republic of (3), Bermuda (1), Bhutan (3), Bolivia (3), Bosnia and Herzegovina (1), Botswana (5), Brazil (2), Brunei (2), Burkina Faso (4), Burundi (4), Cambodia (3), Cameroon (12), Canada (7), Chile (2), China (146), Colombia (3), Congo (3), Congo, Democratic Republic of the (13), Costa Rica (3), Côte d'Ivoire (5), Cuba (1), Czech Republic (1), Denmark (2), Djibouti (1), Dominican Republic (3), Ecuador (1), England (2), Ethiopia (10), Fiji (2), France (4), Gambia, The (1), Georgia (1), Germany (5), Ghana (1), Greece (1), Guinea (1), Guinea-Bissau (1), Haiti (2), Hungary (1), India (23), Indonesia (3), Iran (2), Ireland, Northern (1), Israel (2), Jamaica (2), Kazakhstan (2), Kenya (35), Kyrgyzstan (1), Lebanon (1), Liberia (1), Lithuania (1), Malawi (9), Malaysia (3), Mali (2), Mauritius (1), Mexico (8), Moldova (16), Morocco (8), Mozambique (4), Myanmar (12), Namibia (10), Nepal (9), Netherlands (7), Netherlands Antilles (1), Niger (1), Nigeria (62), Norway (2), Pakistan (3), Paraguay (2), Peru (5), Philippines (12), Poland (2), Romania (2), Russia (14), Rwanda (6), Samoa, American (1), Scotland (1), Senegal (9), Serbia and Montenegro (1), Seychelles (2), Sierra Leone (1), Singapore (3), South Africa, Republic of (29), Spain (3), Sri Lanka (1), St Kitts and Nevis (1), Sudan (2), Surinam (1), Swaziland (7), Sweden (1), Switzerland (10), Syria (1), Taiwan (1), Tanzania (11), Thailand (9), Togo (1), Trinidad and Tobago (2), Uganda (14), Ukraine (28), United Kingdom (32), United States of America (74), Uruguay (1), Uzbekistan (1), Venezuela (4), Vietnam (5), Zambia (18), Zimbabwe (26).

# International HIV/AIDS Alliance

We are an innovative alliance of nationally based, independent, civil society organisations united by our vision of a world without AIDS.

We are committed to joint action, working with communities through local, national and global action on HIV, health and human rights.

Our actions are guided by our values: the lives of all human beings are of equal value, and everyone has the right to access the HIV information and services they need for a healthy life.

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# The Global Network of People Living with HIV (GNP+)

The Global Network of People living with HIV (GNP+) is a global network for and by people living with HIV.

Its mission is to improve the quality of life of people living with HIV.

The vision is a powerful and united worldwide social movement of people living with HIV, with the leadership and voices of people living with HIV at the centre of the HIV response.

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