



**IATT**

THE INTERAGENCY TASK TEAM

The Interagency Task Team on the Prevention and Treatment of HIV Infection in Pregnant Women, Mothers and Children



# 10

## Community Engagement:

- a. A Guide for Ministries of Health (MOHs)
- b. Frequently Asked Questions for Civil Society Organisations to Use in Dialogue with Ministries of Health

## Quick Checklist

✓ **Quick Checklist:** Has my country..

- |   |   |
|---|---|
| <input type="checkbox"/> Identified our 'communities' to engage with  | <input type="checkbox"/> Budgeted community engagement activities in national strategic documents   |
| <input type="checkbox"/> Mapped the structures in place to support community engagement                               | <input type="checkbox"/> Implemented community engagement activities with community stakeholders, especially women living with HIV  |
| <input type="checkbox"/> Consulted with women living with HIV on Option B/B+  | <input type="checkbox"/> Committed to using and supporting ongoing evidence-gathering to make sure that the voices and experiences of communities are heard and addressed |
| <input type="checkbox"/> Developed clear communication lines and materials with community stakeholders on Option B/B+ | <input type="checkbox"/> Adapted and/or used community engagement indicators to monitor progress  |
| <input type="checkbox"/> Highlighted community engagement activities in revised national strategic documents          |   |

### 10a.1 Background

#### Who is this for?

This guide is intended to help Ministries of Health better engage communities as they contemplate, plan for, and/or implement a policy change towards Option B/B+ as the national strategy for ending vertical transmission of HIV (also known as “EMTCT”) and promoting the health of mothers living with HIV.

#### What is “community engagement” in the context of Option B/B+?

Community engagement refers to the process where the “community” (especially including women living with HIV) works collaboratively with national and local health authorities, facility and community based medical service providers, legislators, advocacy groups, and donors to develop, implement, and monitor Global Plan related care.

Involving communities in national level discussions around planning for and implementing the transition to either Option B/B+ means that community members become a key partner in:

- Increasing the uptake of EMTCT services through demand creation and providing peer support

- Improving the supply of EMTCT services through task shifting to community cadres (community health workers, mentor mothers, lay counselors, etc.)
- Monitoring EMTCT service quality and holding providers accountable
- Creating an enabling environment for EMTCT scale-up by empowering women and their communities to access health care under a rights-based approach

## Why should Ministries of Health engage communities when planning for and implementing a shift to Option B/B+?

**Communities need a clear understanding of proposed changes.** For any programme or policy change to be successful, the communities affected must have a clear understanding of the current policy and changes being proposed so that they can give input and participate in decision-making and implementation.

**Communities are key EMTCT stakeholders.** Many community organisations and networks are involved in delivering EMTCT services (e.g. faith-based organisations (FBO)), educating community members about EMTCT services (e.g. community-based organisations), and providing supportive services (e.g. mentor mother programmes and support groups). As such, they are key stakeholders in EMTCT programmes. They must be involved in the planning and implementing of Option B/B+ programmes because they are the ones who will be educating community members and providing services.

**Involving communities ensure that voices of women living with HIV are heard when developing and monitoring programmes and policies that impact them directly.** Involving communities, especially women living with HIV, when considering, planning and/or implementing a programmatic change towards Option B/B+, ensures that programme beneficiaries can contribute to the resulting programmes and policies. This ensures that programmes meet the needs of women living with HIV and will empower them to seek services. Additionally, engaging women living with HIV in accountability efforts can ensure that programmes continue to meet the needs of women living with HIV.

### Key Principle

Ensure that communities, especially women living with HIV, are meaningfully engaged throughout the continuum of the process, from planning to implementation to ongoing monitoring and accountability.

## 10a.2 Five Phases of Community Engagement

### Phase 1: Planning

#### Step 1

**Determine who the “community” is and who you want to and/or should engage in this effort.**

- Consider the main stakeholders of programmes to prevent vertical transmission of HIV in your country, including women living with HIV, their partners and families, care providers in the facility and in the community, networks and organisations of people living with HIV, community-based organisations, faith-based organisations, etc.
- Consider how the EMTCT response is coordinated in your country (e.g. National AIDS Advisory Council, PMTCT Technical Working Group, Country Coordinating Mechanism, etc.). Identify the civil society representatives on those bodies.
- Understand what roles within current EMTCT efforts are played by civil society, including networks of women living with HIV, mentor mothers, faith-based organisations, and community-based organisations (e.g. demand creators, service providers, advocates, beneficiaries, etc.).
- Once you have identified the key community stakeholders, ensure they are well represented and involved in the two steps described below.

#### Step 2

**Assess your country’s national policy, legal and programme environment.**

- Assess what structures exist and should be used to support community engagement (e.g. National AIDS Advisory Council, PMTCT Technical Working Group, Country Coordinating Mechanism, etc.).
  - If there is no formal community engagement mechanism, develop a mechanism in the Option B/B+ plan.
- Consult women living with HIV about whether an Option B/B+ regimen takes into account their values, experiences, concerns, and priority needs.
  - Please note that such evidence may already exist in the form of national assessment reports (e.g. People Living with HIV Stigma Index, Missing the Target Reports, any national level consultations, etc.).
- Determine what kind of information women living with HIV, their communities, and caregivers already have about Option B/B+.

- If such evidence does not exist, inform organisations and networks of people living with HIV about where you are in the process of switching to Option B/B+ and consult the community about the aforementioned issue. This is a prime opportunity to partner with community members to conduct this assessment.
- Develop clear communication with community groups throughout the process (i.e. informing communities that a policy change is being considered, where you are in the process of thinking about this policy change, the advantages/disadvantages of the policy change to Option B/B+, what changes will be implemented if Option B/B+ is chosen, and how communities can be involved in the process of shifting to Option B/B+). At a minimum, it will be very important to ensure that communities understand what Option B/B+ is and what the differences are between Option B/B+ and current treatment regimens.
- After ensuring that the communities have enough information about Option B/B+, give the community an opportunity to share their feedback and potential concerns with you.

### Step 3

#### **Improve the level and quality of involvement of communities in the move toward Option B/B+.**

- If your country has already decided to move towards Option B/B+ and will be updating a national strategy accordingly, be sure that it includes a strong community engagement component. Minimum community engagement activities include the following:
  - Establish and strengthen community-based support services (including FBOs) to provide adherence, counselling, nutrition, referrals to existing support services, etc.
  - Train community workers (e.g. people living with HIV, community health workers, mentor mothers, peer educators, etc.) to assist in delivering supportive services within facilities and communities and to ensure linkages to and retention in facility care.
  - Support and provide community education and awareness in the following areas:
    - Identify and/or provide suitable IEC materials to community workers and community groups about Option B/B+ or develop them with the leaders of community groups
    - Provide resources and training to community workers and groups to enable them to create awareness about the areas listed
  - Strengthen and encourage community-led programme accountability
- Develop SMART<sup>b</sup> activities, inputs, outputs, outcomes, objectives and goals in relation to the aforementioned minimum community engagement activities.

<sup>b</sup> Specific, measurable, attainable, realistic and time-bound

- Adequately budget for the aforementioned minimum community engagement activities in national plans.
  - Ensure that staff are available to support partnerships with communities and to facilitate/coordinate, as needed, the aforementioned community engagement activities

## Phase 2: Implementation

Implement Steps 1-3 above and the affiliated plans in partnership with communities, especially networks of women and men living with HIV, civil society, and all relevant and appropriate stakeholders.

## Phase 3: Alignment into the national response to HIV (integration/coordination)

### Step 1

**In cooperation with partners, ensure that the community engagement principles and activities are integrated into the broader work in the national response to HIV, which includes:**

- national strategic plans
- resource mobilisation for HIV, development and economic empowerment
- legal and policy reform
- health and communities systems strengthening
- mainstreaming HIV into sectoral work

### Step 2

**Ensure coordination, constructive dialogue, and information-sharing between diverse groups of partners regarding the community engagement activities.**

### Step 3

**Foster partnerships through inclusive coordination mechanisms that are adequately resourced. Existing coordination mechanisms (e.g. National AIDS Advisory Council, EMTCT Technical Working Group, Country Coordinating Mechanism, etc.) may need to be reviewed and strengthened, and civil society coordination bodies may have to be developed and supported.**

## Phase 4: Continuous evidence gathering; make use of existing data

### Step 1

**Gather evidence on a continuous basis at all phases of implementation (i.e. during development, roll-out, adaptation and improvement) with the meaningful involvement and leadership of communities, especially women living with HIV.**

- Example 1: The Missing the Target (MTT) 9 report assesses EMTCT programmes in ten countries and discusses key actions needed to reach EMTCT goals. Using such existing data and recommendations can support the programme or policy change towards Option B/B+. Additionally, re-using the MTT model to assess the progress and success of the shift towards Option B/B+ after plans are implemented can further support measurement of the effectiveness and impact of the plans.
- Example 2: The PLHIV Stigma Index can provide invaluable evidence on what actions need to be taken towards reducing stigma and discrimination. Re-implementing the PLHIV Stigma Index after those actions have taken place can support measurement of the effectiveness and impact of those actions.



## Phase 5: Monitoring and evaluation (M&E)

### Step 1

**Use appropriate indicators for community engagement, especially with respect to the move towards Option B/B+, in the following areas:**

- Establish and strengthen community-based support services (including FBOs) in relation to Option B/B+.
- Train community workers (e.g. people living with HIV, community health workers, mentor mothers, peer educators, etc.) to assist in delivering supportive services within facilities and communities and to ensure linkage to and retention in facility care.
- Support and provide community education and awareness in the following areas:
  - Identify and/or provide suitable IEC materials to community workers and community groups about Option B/B+ or develop them with the leaders of community groups.
  - Provide resources and training to community workers and groups to enable them to create awareness about the areas listed.
- Strengthen and encourage community-led programme accountability.

### Step 2

**Dedicate adequate resources (human, technical and financial) in the operationalisation of an M&E framework and mechanism for community engagement in the Option B/B+ process.**

### Step 3

**Ensure that M&E of community engagement is an on-going aspect of every action.**

### Step 4

**Ensure that communities can lead or participate in M&E efforts.**



## Resources

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- 1 IATT Toolkit: Key Considerations Document (see Section 1)
- 2 Advancing the Sexual and Reproductive Health and Rights of PLHIV - A Guidance Package (2010). Available at: [www.gnpplus.net/programmes/sexual-and-reproductive-health-and-human-rights/policy-guidance](http://www.gnpplus.net/programmes/sexual-and-reproductive-health-and-human-rights/policy-guidance).
- 3 Good Practice Guide: Greater Involvement of People Living with HIV (GIPA) (July 2010). Available at: <http://www.gnpplus.net/en/programmes/empowerment/gipa-report-card/1642-good-practice-guide-greater-involvement-of-people-living-with-hiv-gipa>
- 4 MTT9: The Long Walk -Ensuring comprehensive care for women and families to end vertical transmission of HIV (December 2011). Available at: <http://www.itpcglobal.org/atomic-documents/11057/11059/MTT9%20report.pdf>
- 5 Positive Health, Dignity and Prevention Policy Framework (2012). Available at: [http://www.gnpplus.net/images/stories/PHDP/GNP\\_PHDP\\_ENG\\_V4ia\\_2.pdf](http://www.gnpplus.net/images/stories/PHDP/GNP_PHDP_ENG_V4ia_2.pdf)

## 10b.1 Background

### Purpose

The purpose of this tool is to equip Civil Society Organisations (CSOs) and Networks of Women/People Living with HIV with the information necessary to actively engage in national level discussions around the transition to offering pregnant women ART through the breastfeeding period (Option B) or for life (Option B+). The questions outlined below provide examples of the important issues that CSOs and Networks should encourage Ministries of Health to answer during the various implementation stages of a new treatment regimen to prevent vertical transmission and support mothers to stay healthy and alive.

### Audience

This tool is intended to be used by members of CSOs and Networks of Women/People Living with HIV. CSOs in this context include community-based organisations, lay workers (e.g. mentor mothers, community health workers, peer counselors etc.), faith-based organisations, treatment activists, youth groups and other groups outside of government and business that are working to further the health and rights of women, children and families.

The tool was developed by the Community Engagement Working Group of the Inter-Agency Task Team on Prevention of HIV Infection in Pregnant Women, Mothers and their Children. The goal is to ensure that communities, especially women living with HIV of reproductive age, are engaged in all stages of the transition to Option B/B+. The purpose of this tool is not to advocate for any particular strategy for preventing vertical transmission, but rather to ensure that the views and concerns of CSOs and Networks of Women/People Living with HIV are seriously considered in the planning, implementation, and ongoing monitoring of service delivery to prevent vertical transmission at the national level.

## PMTCT Options

**Table 1:** What is the difference between Option A, Option B, and B+?

	WOMEN WITH CD4 COUNT ABOVE 350 CELLS/MM <sup>3</sup>	WOMEN WITH CD4 COUNT BELOW 350 CELLS/MM <sup>3</sup>	CHILD RECEIVES
<b>OPTION A</b>	<p>During pregnancy: AZT starting as early as 14 weeks of pregnancy</p> <p>At delivery: single-dose NVP and first dose of AZT/3TC</p> <p>After delivery: daily AZT/3TC through 7 days postpartum</p>	Triple ARVs started as soon as diagnosed and continued for life	Daily prophylaxis (NVP) from birth until 1 week after all breastfeeding has finished; or, if not breastfeeding or if mother is on treatment, through age 4–6 weeks
<b>OPTION B</b>	Triple ARVs starting as early as 14 weeks of pregnancy continued through childbirth (if not breastfeeding) or until 1 week after all breastfeeding has finished		Daily prophylaxis (NVP or AZT) from birth through age 4–6 weeks regardless of infant feeding method
<b>OPTION B+</b>	Triple ARVs started as soon as diagnosed and continued for life		



**Table 2:** What are the benefits and potential challenges of Options B/ B+?

	POTENTIAL BENEFITS OF OPTION B	POTENTIAL CHALLENGES OF OPTION B
<b>FOR A WOMAN LIVING WITH HIV</b>	<p>Increased access to treatment because:</p> <ul style="list-style-type: none"> <li>• Women do not have to wait for a CD4 count test before starting treatment.</li> <li>• Treatment can be started at primary care health facilities, reducing the distance that women have to travel to receive treatment.</li> </ul> <p>Women continue same treatment regimen between pregnancy/postpartum period (unlike Option A).</p> <p>Triple ARVs provided throughout breastfeeding period may encourage women to breastfeed longer improving child health, reducing stigma and discrimination, and reducing household expenditures for infant formula.</p>	<p>Potential impact on later treatment: women might develop resistance from starting ARVs during pregnancy and then stopping after breastfeeding that could limit her treatment choices later.</p> <p>A CD4 count test is needed after the risk of vertical transmission has ended (i.e. after childbirth or breastfeeding) to decide if the woman should continue taking ART for her own health.</p>
<b>FOR THE MINISTRY OF HEALTH AND OTHER HEALTHCARE PROVIDERS</b>	<p>Simplifies treatment as the same regimen is provided to all women.</p>	<p>Higher cost in comparison to Option A.</p> <p>Lack of involvement of women living with HIV and their communities in decisions relating to Option B at the national level.</p>

POTENTIAL BENEFITS OF OPTION B+	POTENTIAL CHALLENGES OF OPTION B+	
<p>Increased access to treatment because:</p> <ul style="list-style-type: none"> <li>• Women do not have to wait for a CD4 count test before starting treatment.</li> <li>• Treatment can be started at primary care health facilities, reducing the distance that women have to travel to receive treatment.</li> </ul> <p>Women may live longer and healthier lives due to starting treatment earlier.</p> <p>Reduced risk of transmitting to HIV-negative sex partner(s).</p> <p>May reduce the risk that a woman will develop resistance to ARVs resulting from stopping and starting ARVs after each pregnancy.</p> <p>Provides extended protection for future pregnancies from the time of conception. This is especially important in settings where women have short inter-pregnancy intervals.</p>	<p>Ensuring women are able to make informed choices around starting treatment for life. Concerns raised that women's choice around when to start lifelong ART, including the choice to decline lifelong ART during pregnancy, may not be respected.</p> <p>Lack of information including treatment literacy tools and counseling messages limits women's ability to make informed decisions on starting lifelong ART during pregnancy.</p> <p>Inadequate psychosocial and nutritional support services to support women in coping with their HIV diagnosis, to continuously take their medications, and to stay connected with health facilities.</p>	<p><b>FOR A WOMAN LIVING WITH HIV</b></p>
<p>Simplifies treatment as:</p> <ul style="list-style-type: none"> <li>• The same regimen is provided to all women regardless of their CD4 count.</li> <li>• There is no change in regimen between pregnancy/postpartum period (unlike Option A).</li> <li>• It does not require mothers, with support of their doctors, to decide whether ART should be stopped or continued after the risk of vertical transmission has ended (as in Option B).</li> </ul>	<p>Sustainability of Option B+: Ability of countries to ensure continuous supply of ARVs and comprehensive prevention of vertical transmission services given the increased demand on HIV treatment services associated with Option B+. This is of particular concern in countries with regular ARV stock-outs.</p> <p>Poor ART adherence and/or women not remaining in HIV clinical care after delivering their child could lead to widespread ARV drug resistance.</p> <p>Equity of offering pregnant women lifelong treatment at higher CD4 counts and not other population groups (i.e. fathers, non-pregnant women).</p> <p>Lack of involvement of women living with HIV and their communities in decisions relating to Option B+ at the national level.</p> <p>Several investments by MOH will be needed in human resources, infrastructure, and supply chain management to effectively scale-up ART services to all sites that provide antenatal care.</p> <p>Policies and procedures will need to be developed to support nurses to effectively initiate and prescribe ART.</p>	<p><b>FOR THE MINISTRY OF HEALTH AND OTHER HEALTHCARE PROVIDERS</b></p>

## 10b.2 What questions must CSOs & networks of women/people living with HIV be asking?

### Involvement of CSOs and networks of women/people living with HIV

**CSOs and Networks of Women/People Living with HIV must be involved in the planning, implementation and monitoring of Option B/B+ to ensure that their perspectives inform the resulting programmes and policies. Meaningfully engaging and supporting CSOs and Networks of Women/People Living with HIV in the development of information materials and data collection tools as well as in the review and analysis of national programme data will result in a better understanding of the issues and will ensure that services meet the needs of women.**

- How will women living with HIV and community organisations be involved in the planning, implementation, monitoring and evaluation of Option B/B+?
- How will people living with HIV and CSOs be involved in delivering services to prevent vertical transmission (i.e. treatment supporters, mentor mothers, etc.)?
- What messages will communities receive about Option B/B+? How will these messages be developed and delivered?
- What resource mobilisation plans are in place to ensure adequate long-term funding of prevention of vertical transmission programmes?



## Counseling and support services

**Systems must be in place to support the provision of counseling and support services to women living with HIV to ensure that they are able to make an informed choice regarding if and when to start treatment and for how long. Women living with HIV must also be offered support services that enable them to adhere to treatment and prevent transmission of HIV to their partners and children. Community structures must also be in place to support women living with HIV outside of the health-care facility by addressing issues such as stigma and discrimination, disclosure, male involvement and gender based violence.**

### At the individual level:

- How will women receive counseling on Option B/B+ (i.e. what messages will they receive, who will provide them with counseling)?
- How are women supported to understand their choices regarding starting lifelong treatment during pregnancy (as is the case in Option B+)? How are they supported if they decline to start treatment for life following this counseling if that is their decision?
- What supportive services and counseling will be offered to women to ensure they are able to continuously take their medication and stay connected with health facilities (adherence counseling, food programmes, etc.?)

### At the community level:

- What plans and strategies is the government using to increase male involvement in maternal and child health programmes in order to support uptake of and adherence to services to prevent vertical transmission?
- What strategies are in place to address gender-based violence related to HIV diagnosis and treatment and to support women who are experiencing gender-based violence?
- What strategies are in place to reduce stigma and discrimination experienced by women living with HIV at health facilities and within the community?

## Ensuring the quality of service delivery

**Plans must be developed to ensure that quality services to prevent vertical transmission are delivered to women living with HIV and governments and health care providers must be held accountable for the quality of the services they deliver. Mechanisms must be in place, which allow the community to provide feedback on the quality of HIV testing, access to and quality of HIV treatment and support services, and the realisation of their sexual and reproductive health rights. Assuring quality will be particularly challenging at primary health care centres and clinics that provide ANC but do not currently provide ART. These facilities are closest to communities but usually have the greatest needs around infrastructure (e.g. lack of water, electricity, means of transport) and human resources (e.g. lack of qualified staff). Recommendations by the community must be meaningfully considered and included in decision-making processes at the national level.**

- How will government ensure there is enough trained staff to implement Option B/B+ (training for health care providers, plans for task shifting, etc.)?
- What is the plan to ensure the quality of HIV testing in antenatal settings to ensure women receive a correct diagnosis?
- What ARV regimen is being considered? Will the same ARV regimen be used in the prevention of vertical transmission and as the first-line ART regimen so that women do not have to switch regimens post-partum?
- What is government doing to ensure universal access to ART by both pregnant women and non-pregnant PLHIV who are eligible for ART under current guidelines (i.e. are funds adequate for drug procurement, supply chain issues addressed, etc.)? What plans are in place to scale-up ART services to primary health care centres and/or clinics that do not currently have these services?
- What are the plans for monitoring development of drug resistance?
- How will government ensure an adequate supply of 2<sup>nd</sup> and 3<sup>rd</sup> line regimens?
- What referral and/or tracking systems are in place between MNCH and ART to make sure women have continued access to ART following delivery? (This may be less of an issue at primary health care centres or clinics where the same provider may do both ANC and ART)
- What infant feeding messages and services will be offered to women post-delivery? How will they differ for women on ART?
- What are plans for ensuring that primary prevention (Prong 1) and family planning needs (Prong 2) receive equal attention and investment?



- How will governments and health providers ensure that the sexual and reproductive health rights and choices of women are protected in family planning and programmes to prevent vertical transmission? Will FP commodities and trained staff be available at primary health care centres and/or clinics?
- What community engagement indicators are being used to track: (1) demand creation, (2) service delivery, (3) accountability and (4) the success/failure of efforts to engage communities?