



Validation of EMTCT of HIV and/or syphilis

Tools and checklists for in-country evaluation of four required components

4		Human rights, gender equality, and engagement of civil society in the EMTCT process
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I. Background

The *Global plan towards the elimination of new HIV infections among children by 2015 and keeping their mothers alive* provided the foundation for the elimination of mother to child transmission effort. The plan focused on a series of specific policy and programmatic measures that countries took to ensure rapid progress towards elimination of new HIV infections in children by 2015. At its 37th meeting in 2016, the UNAIDS Programme Coordinating Board adopted a new strategy to end the AIDS epidemic as a public health threat by 2030. The UNAIDS 2016–2021 Strategy is aligned with the newly identified Sustainable Development Goals (SDGs), which set the framework for global development policy over the next 15 years, including ending the AIDS epidemic by 2030. In 2007 WHO launched an initiative for the global elimination of congenital syphilis, outlined in *The global elimination of congenital syphilis: rationale and strategy for action*.

A key consideration for validation of a country for eliminating mother to child transmission of HIV and syphilis is that the interventions to reach the targets have been implemented in a manner consistent with international, regional and national human rights standards. These standards include human rights in relation to autonomy in decision making, informed consent, respect of privacy and confidentiality, freedom from violence, abuse and coercive practices and meaningful participation. The United Nations (UN) and regional human rights systems have in place a significant body of legal instruments, including treaties, conventions, general comments, concluding observations and case law for the protection of human rights, including the right to enjoyment of the highest attainable standard of health (“right to health”), for all people without discrimination, among them women and children and all people living with HIV. At the national level, constitutions, health care laws, patient’s rights laws and other legal instruments ensure national protection of human rights and gender equality.

This tool presents guidance for assessment of the following components of the validation process: (1) human rights; (2) gender equality; and (3) civil society and community engagement.

Human rights

A non-negotiable consideration for validation of a country is that the interventions to reach the targets have been implemented in a manner consistent with international, regional and national human rights standards. The UN and regional human rights systems have in place a significant body of legal instruments, including treaties, conventions, general comments, concluding observations and case laws for the protection of human rights, including the right to enjoyment of the highest attainable standard of health (“right to health”) and other related human rights that shall be applicable to all people without discrimination, including women and children and people living with HIV. At the national level, constitutions, health-care laws, patient’s rights laws and other legal instruments ensure national protection of human rights. It is important to note that the principles underpinning human rights all need to be upheld including universality, inalienability, indivisibility, interdependency, non-discrimination, equality, participation, accountability and rule of law.

Several universal and regional health and human rights agreements have established obligations applicable to various State actors, including ministries of health, health institutions and health-care workers with regard to the respect, protection and fulfilment of human rights in relation to health more broadly and EMTCT of HIV specifically (1,2). National human rights protection systems consist of legal frameworks, institutions, policies, procedures and actors, and they have been established to ensure that international, regional and national human rights are respected, protected and fulfilled, including human rights of women, children and other groups in situations of vulnerability.

Gender equality

Gender equality considerations are particularly pertinent in the context of vertical transmission of HIV and syphilis, as gender norms and practices can significantly shape the enjoyment of sexual and reproductive health (SRH) and rights of women, and health outcomes for their children. Promoting and ensuring gender equality can significantly influence the opportunities of women and girls to access necessary information and services, make autonomous decisions about their sexuality and reproduction, and protect themselves against HIV and sexually transmitted infections (STIs).

Community engagement

Greater involvement of people living with HIV (GIPA) is a principle that aims to realize the human rights and responsibilities of people living with HIV, including their right to health, and the right to participation in decision-making processes that affect their lives (3). There is consensus in the global community that engaging people living with HIV has many benefits, and that involvement should be multidimensional, including in the policy-making process, programme development and implementation, advocacy and service delivery. Engagement and participation of women living with HIV, in particular, in the formulation of health laws, policies, programmes, and monitoring and evaluation (M&E) systems that affect them ensures better, more effective programming and that women living with HIV and syphilis that women get the treatment they need to keep themselves well and their children free from HIV and syphilis. Consequently, community engagement advances efforts for the EMTCT of HIV and syphilis.

Commonly identified barriers that need to be comprehensively addressed for rights-based EMTCT of HIV and syphilis include the following:

- criminalization of vertical transmission
- mandatory or coerced testing and treatment
- lack of informed consent
- forced and coerced abortion, contraception and/or sterilization
- lack of confidentiality and privacy
- lack of equality and non-discrimination
- lack of availability, accessibility, acceptability and quality of services
- lack of accountability and absence of participation and community engagement
- gender-based violence
- lack of access to justice, remedies and redress.

II. SCOPE OF THE TOOL

The following instrument measures readiness for EMTCT validation and progress towards achieving a human rights based approach to the prevention of mother-to-child transmission of HIV and syphilis as well as implementing good practices regarding gender equality and community engagement. The tool is a collection of key human rights issues identified by women living with HIV as the main barriers to achieving EMTCT of HIV and syphilis.

The absolute non-negotiables include grave or systematic human rights abuses, including forced sterilizations, contraception or abortion and mandatory testing, as well as lack of Government due diligence in redressing such abuses. No country can be validated for EMTCT of HIV and/or syphilis if there are grave or systematic human rights violations in the context of EMTCT.

Governments have an obligation to respect, protect and fulfil human rights and are the primary duty bearers ensuring that the minimum human rights standards for PMTCT programming are met. As rights holders and representatives of rights holders, clients of health services, including women living with HIV, and civil society organizations must also have an opportunity to independently reflect on policy and practice in the PMTCT context to identify rights violations and to support the identification of gaps in implementation and realization of rights protections, gender equality and community engagement.

The following tool and checklist is designed to provide data for the purposes of evaluating whether a PMTCT programme has met the requirements of global minimum criteria 4: “Validation criteria must have been met in a manner consistent with gender equality and basic human rights considerations.”

The questionnaire can also serve as an important **pre-evaluation tool** to assess whether the country will meet the minimum required standards in advance of an application for validation.

III. METHODOLOGY

The assessment methodology proposes the following two mutually complementary data collection methodologies:

1. Desk review including review of national programme policies. Review of the international and regional human rights and gender equality instruments (conventions, treaties, protocols) the country has signed and/or ratified (i.e. Convention on the

Elimination of all Forms of Discrimination Against Women [CEDAW], Convention on the Rights of the Child [CRC], Inter-American Convention on Human Rights, Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa), and policy and programmatic declarations, such as Global Strategy for Women's, Children's and Adolescents' Health 2016-2030 (including guiding principles), and the Strategic Framework for the elimination of new HIV infections among children in Africa by 2015 and keeping their mothers alive.

1. Review of national constitutions and laws for human rights protection, including protection of the right to health, women's and children's rights, rights of adolescents and young people, rights of key populations and sexual and reproductive rights.
 - a. Review of country reports to human rights bodies (shadow reports submitted by nongovernmental organizations) and country reports to other relevant bodies (i.e. the Global AIDS Response Progress Reporting [GARPR] process, and its National Commitments and Policy Instrument, Unified Budget, Results and Accountability Framework [UBRAF] reports), and other documents that provide insight into countries' performance on human rights, women's rights, gender equality and HIV in general, and in relation to EMTCT in particular (including, where available, Stigma Index reports). There must be a sufficient opportunity for civil society and human rights groups to submit statements, shadow reports, research and other submissions for inclusion in the submission or to be provided directly to the validation team.
 - b. Concluding observations, recommendations, judgments received from international, regional, and national health and human rights bodies (i.e. treaty monitoring bodies, Universal Periodic Review [UPR] recommendations, responses and reports from the UN Special Rapporteur, ombudsperson reports, national court judgments). Interviews with relevant stakeholders will assess what the State has done to respond to issues raised by human rights bodies.

These documents are also in the public sphere and can be easily retrieved by the Regional Validation Committee/Team (RVC/RVT).

3. Stakeholder interviews: Semi-structured interviews with key officials with human rights, gender equality and community engagement functions, including the human rights desk, ombudsperson, bureau of gender affairs, ministries of foreign affairs, legislators, law enforcement agents, judges, among others, to collect information on the existence and functioning of government structures and mechanisms related to human rights and EMTCT.
 - a. Semi-structured interviews with civil society representative organizations, including organizations and advocates of women living with HIV, young people living with HIV, other people living with HIV and women's groups, regarding their views on the protection, promotion and fulfilment of human rights related to HIV, women's rights, sexual and reproductive rights and gender equality, and the status of community engagement in general, and related to EMTCT programmes and services in particular.
 - b. Semi-structured interviews with HIV and EMTCT programme managers and health services providers, including nurses and midwives regarding their views on the protection, promotion and fulfilment of human rights related to HIV, women's rights, sexual and reproductive rights and gender equality, and the status of community engagement in general and related to the EMTCT programmes and services in particular.

IV. CHECKLIST

(COMPLETE ONE CHECKLIST AT EACH LEVEL OF GOVERNMENT ASSESSMENT)

- National level site
- Subnational level site
- Service delivery site

Name of site _____

Date of visit _____

		Yes	No	Unable to verify	Comments
1	Non-criminalization of HIV/syphilis transmission				
	Are there laws that criminalize any of the following acts?	Y	N	U	
	a) potential or perceived exposure to (1) HIV?	Y	N	U	
	(2) syphilis?	Y	N	U	
	b) Are there specific laws or judicial precedents that criminalize non-disclosure of HIV/syphilis status to sexual partners?	Y	N	U	
	c) Are there prosecutions for non-disclosure, exposure or transmission of (1) HIV?	Y	N	U	
	(2) syphilis?	Y	N	U	

		Yes	No	Unable to verify	Comments
2	Voluntary HIV and syphilis testing and treatment				
	a) Are there laws or judicial precedents, regulations and/or policies prohibiting any of the following during antenatal care?				
	Mandatory testing for HIV and syphilis?	Y	N	U	
	Mandatory treatment for HIV and syphilis?	Y	N	U	
	b) Are women/pregnant women informed that they have a right to refuse testing or treatment for HIV or syphilis?	Y	N	U	
	c) Are there recent documented reports of mandatory testing and/or treatment of women/pregnant women for HIV and syphilis?	Y	N	U	
3	Informed consent				
	a) Are there laws or judicial precedents, regulations and/or policies requiring informed consent directly from women and key populations in the maternal and child health (MCH) setting (including FP, SRH, STI, GBV, HIV C&T, ART and other HIV services)?	Y	N	U	
	b) Are there laws or judicial precedents, regulations and/or policies recognizing and protecting adolescents' right to freely decide whether or not to receive health services/treatment without parental/guardian consent?				
	c) Are there recent documented reports of violation of informed consent of women and adolescents accessing EMTCT and other HIV/SRH services? (including third party authorization requirement from husband, partner or parent)	Y	N	U	

		Yes	No	Unable to verify	Comments
4	Forced, coerced and otherwise involuntary sterilization, contraception and/or abortion				
	a) Are there laws or judicial precedents, regulations and/or policies prohibiting forced, coerced and otherwise involuntary sterilization, contraception and/or abortion?	Y	N	U	
	b) Are there recent documented reports of involuntary sterilization, contraception and/or abortion (without the consent of women living with HIV or syphilis)?	Y	N	U	
5	Confidentiality and privacy				
	a) Are there laws, regulations and/or policies that require confidentiality and non-disclosure of HIV status in health-care settings?	Y	N	U	
	b) Are there recent documents or reports of disrespect of privacy and confidentiality in health-care settings?	Y	N	U	
6	Equality and non-discrimination				
	a) Are there laws or judicial precedents, regulations and/or policies that guarantee equality and non-discrimination, which include specific provisions on:				
	(1) sex and/or gender equality	Y	N	U	
	(2) HIV and syphilis status;	Y	N	U	
	(3) children	Y	N	U	
	(4) key populations, and call for the elimination of discrimination?	Y	N	U	
	b) Are there documented cases or reports of discrimination, disrespect of privacy and confidentiality in health-care settings?	Y	N	U	

		Yes	No	Unable to verify	Comments
7	Accountability, community engagement and participation of people affected by HIV and other key populations				
	a) Are there laws, regulations and/or policies on ensuring accountability in relation to EMTCT, community engagement, participation and greater involvement of people/women affected by HIV?	Y	N	U	
	b) Are networks of women living with HIV involved in the development and evaluation of national laws, regulations, policies and plans for prevention of mother-to-child transmission (PMTCT) programmes?	Y	N	U	
	c) Does the national annual PMTCT progress report include civil society/community analysis of progress?	Y	N	U	
	d) Is feedback from civil society/community reflected in revised national PMTCT operational plans?	Y	N	U	
	e) Do facilities have accountability mechanisms (such as community dialogues or health committees, charters, scorecards) to support efforts at improvement of PMTCT services?	Y	N	U	
8	Gender -based violence				
	a) Are there laws, regulations, policies or judicial precedents prohibiting or banning all forms of violence against women and girls?	Y	N	U	
	b) Are there national plans of action and/or a policy for prevention of and response to violence against women?	Y	N	U	
	c) Are there recent documents or reports of violence against women?	Y	N	U	

		Yes	No	Unable to verify	Comments
9	Availability, accessibility, acceptability and quality of services				
	a) Are there laws, regulations and/or policies or judicial precedents on ensuring availability, accessibility, acceptability and quality of PMTCT services?	Y	N	U	
	b) Do PMTCT programmes have strategies to address common barriers to access that women living with HIV and their families face, such as:	Y	N	U	
	(1) Are there frequent stock-outs of medicines?	Y	N	U	
	(2) Are there signs of stigma and discrimination in health-care settings?	Y	N	U	
	(3) Are there costs for testing and/or treatment?				
	a) HIV?	Y	N	U	
	b) syphilis?	Y	N	U	
	a) antenatal care services?	Y	N	U	
	(4) shortage of trained health-care workers	Y	N	U	
	(5) distance and travel costs to health facilities?	Y	N	U	
	c) Are women living with HIV able to access antenatal or PMTCT services without fear of stigma or discrimination?	Y	N	U	
	d) Does the PMTCT programme offer quality services that include:				
	(i) pre- and post-test counselling (if required in country)	Y	N	U	
	(ii) counselling and psychosocial support for HIV and/or syphilis positivity?	Y	N	U	

	Yes	No	Unable to verify	Comments
(iii) infant-feeding guidance?	Y	N	U	
(viii) assistance for women with disabilities?	Y	N	U	
(ix) services for indigenous women?	Y	N	U	
e) Does the PMTCT strategy review the accessibility and acceptability of services for:				
(i) young women of reproductive age?	Y	N	U	
(ii) unmarried women?	Y	N	U	
(iii) women living with HIV?	Y	N	U	
(iv) sex workers?	Y	N	U	
(v) women who use drugs?	Y	N	U	
(vi) lesbian, bisexual or queer women?	Y	N	U	
(vii) transgender people?	Y	N	U	
f) Are there initiatives in place to ensure access to services for these populations?	Y	N	U	
g) Are there laws, regulations and/or policies or judicial precedents guaranteeing equal and universal access to SRH services including maternal health services, family planning services for women living with HIV and/or affected by HIV, with special attention to populations of women in vulnerable situations (including ethnic or religious minorities, indigenous women, women with disabilities, poor women, migrant women, unmarried women, sex workers, women who use drugs, other vulnerable women)?	Y	N	U	
h) Are health-care workers and health facility personnel trained in human rights issues including:				
(i) sexual and reproductive rights?	Y	N	U	

		Yes	No	Unable to verify	Comments
	(iii) informed consent?	Y	N	U	
	(iv) patient confidentiality and privacy?	Y	N	U	
	(v) respectful maternal care?	Y	N	U	
	(vi) gender-based violence?	Y	N	U	
	(vii) promoting gender equality?	Y	N	U	
	i) Are there laws, policies and/or practices in place that criminalize behaviours or acts that are particularly relevant for key populations that are especially vulnerable to HIV or syphilis, such as:				
	(i) sex work?	Y	N	U	
	(ii) drug use?	Y	N	U	
	(iii) same-sex sexual behaviour?	Y	N	U	
	(iv) cross-dressing or any other behaviours or acts related to (trans) gender expression?	Y	N	U	
10	Access to justice, remedies and redress				
	a) Are there laws, regulations and/or policies or judicial precedents ensuring access to justice, remedies and redress , including pro bono legal services?	Y	N	U	
	b) Are there procedures or mechanisms to report human rights violations related to HIV care?	Y	N	U	
	c) Are there any grievance mechanisms in your country for redress of human rights violations against women living with HIV?	Y	N	U	
	d) Is there a way for women living with HIV to hold service providers accountable for any violation of human rights in the context of PMTCT services?	Y	N	U	
	e) Are there institutional barriers to accessing these mechanisms?	Y	N	U	

		Yes	No	Unable to verify	Comments
	f) Are there social, religious or cultural barriers to accessing these mechanisms, left unaddressed by laws, regulations or policies?	Y	N	U	
	g) Does the PMTCT programme include initiatives to increase women's awareness of their human rights, including their sexual and reproductive rights?	Y	N	U	
	h) Are human rights violations within the PMTCT setting documented and monitored?	Y	N	U	
	i) Have there been sanctions or reparations for violations of rights in context of PMTCT programmes?	Y	N	U	

Summary of findings:

Required table to include in country report and regional validation team (RVT) reports:

Non-negotiable in Human rights, gender equality, and civil society engagement

Issue	Yes	No	If yes, does this affect the decision to validate for elimination? Why? What are the suggested recommendations for the country?
Is there criminalization of vertical transmission?			
Is there mandatory or coerced testing and/or treatment for HIV and syphilis?			
Is there lack of informed consent?			
Is there forced and coerced abortion, contraception and/or sterilization?			
Is there a lack of confidentiality and privacy?			
Is there lack of equality and non-discrimination?			
Is there lack of availability, accessibility, acceptability and quality of SRH and ANC services?			
Is there a lack of accountability and absence of participation and community engagement?			
Are there laws to protect women from gender-based violence?			
Is there a lack of access to justice, remedies and redress?			