GLOBAL GUIDANCE ON CRITERIA AND PROCESSES FOR VALIDATION: ELIMINATION OF MOTHER-TO-CHILD TRANSMISSION OF HIV, SYphilis AND HEPATITIS B VIRUS

WEB ANNEX H

ANALYSIS GUIDANCE FOR HUMAN RIGHTS, GENDER EQUALITY AND COMMUNITY ENGAGEMENT IN VALIDATION
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PURPOSE

This is a step-by-step guide for the national assessment for validation of elimination of vertical transmission of HIV, syphilis and hepatitis B virus (HBV) in the area of human rights, gender equality and community engagement (HR GE CE). This annex supports the National Validation Committee (NVC) to gather evidence using the focus group discussion guide in this annex and the Human rights, gender equality and community engagement assessment and verification tool provided in Web Annex G. Further, this annex provides guidance on synthesizing the data collected for reporting in the initial validation report. The report template for initial validation is available as Web Annex C.

INTRODUCTION

In the course of the NVC’s work to gather evidence and prepare the initial validation report, it is essential to maintain close collaboration with, and input from, the community to assess the situation of human rights, gender equality and community engagement. A collaborative process of information gathering and analysis supports building the capacity of governments to deliver on their human rights obligations and the capacity of communities to claim their health rights. Thus, the process:

- empowers women as rights holders
- strengthens diverse women’s participation in national efforts that reflect their realities and rights
- creates a platform for dialogue and consensus around priorities and ways forward
- provides vital information and feedback from women who use health care services on how to improve programme and service quality
- strengthens the enabling environment for efforts supporting prevention of vertical transmission, also known as prevention of mother-to-child transmission (PMTCT).

A successful assessment may ultimately require allowing different community groups to complete the tool and independently analyse findings and then reach consensus about the issues and findings through a facilitated multi-stakeholder consultation. The recommended steps for completing the HR GE CE assessment are outlined in the Global guidance on criteria and processes for validation: elimination of mother-to-child transmission of HIV, syphilis and hepatitis B virus. It is also important to consider that the nature of the issues under assessment can be sensitive and involve risk for both individuals and health workers responding to the assessment questions. A well-managed process creates a safe space for individuals to come forward to share insights or raise concerns on sensitive or challenging issues.
SHARED PRINCIPLES

Drawing on public health principles and evidence-based good practice, it is recommended to follow these fundamental principles throughout the assessment process.

Do no harm

In any efforts to engage and collaborate with women around sensitive topics, including HIV status, human rights violations and experiences of inequality, the principle of “do no harm” must be adhered to. The process must make provisions to ensure, at a minimum: 1

- safety, privacy and confidentiality of all participants;
- no harm or retaliation against individual or organizational participants or members of the assessment team;
- availability of gender and culturally sensitive services and sources of support, remedy and redress for individuals reporting human rights violations; and
- mechanisms and strategies to reduce any possible distress caused by the data collection.

Meaningful inclusion

Validation processes should be conducted in line with the greater involvement of people living with HIV (GIPA), 2 a guiding principle that calls for the active and meaningful participation of people living with HIV in the inception, development, implementation, monitoring and evaluation of policies and programmes. Networks of women living with HIV and organizations supporting women with HIV, syphilis and HBV must be meaningfully engaged as early in the process as possible. The selection of people to engage in the national validation process should, as much as possible, be led by these networks and organizations, and their engagement should not be tokenistic.

Transparency and equality

The process of data gathering with the community should be collaborative, fair and transparent. Adequate and equitable time and support for preparation must be afforded to plan the process. The community should be empowered to select their own representatives – paying attention to principles of gender equality, inclusiveness and diversity – and propose methods of participation in the process. These organizations should be provided with financial and technical support, if needed, to gather evidence independently, analyse issues and provide recommendations for consideration by the NVC.

STEP-BY-STEP: UNDERSTANDING THE PROCESS FOR VALIDATION

The HR GE CE Assessment in Web Annex G compiles the minimum information required to review whether programmes to prevent vertical transmission have been carried out in a manner which meets international human rights standards and promotes gender equality, and are therefore eligible for validation of elimination of vertical transmission of HIV, syphilis and/or HBV.

Involving individuals and organizations with human rights and gender equality expertise, including community stakeholders and human rights practitioners, will also be essential to ensure the correct analysis of issues. Importantly, this will also ensure that where human rights concerns or violations and underlying gender inequalities are identified, there are appropriate strategies to address these violations, including safety for groups and individuals reporting rights abuses and facilitation of accountability pathways.

**Step 1: Engage the community**

As a general rule, the schedule of the validation process should be announced well in advance to a wide range of stakeholders so that they can prepare their contributions to the process.

As outlined in the *Global guidance on criteria and processes for validation: elimination of mother-to-child transmission of HIV, syphilis and hepatitis B virus*, the NVC should gather evidence for the validation assessment in a collaborative and consultative manner, involving all key stakeholders. This should include robust participation throughout the validation process from organizations representing women who use health care services, including networks of women living with HIV or HBV, networks of key populations, organizations working on sexual and reproductive health and rights and other women’s organizations.

The engagement of networks of women and civil society to provide expertise and input can occur in a variety of ways, including through focus groups, stakeholder interviews or independent reports to feed into the national assessment (see Step 3).

**Step 2: Completing the assessment tool**

The focus group discussion guide is a printable tool at the end of this document which can be used to collect qualitative information on the situation of HR GE CE in a country. Web Annex G provides an assessment tool which may be used to compile and analyse information on the 10 topics for HR GE CE.

During the assessment process outlined in the *Global guidance on criteria and processes for validation: elimination of mother-to-child transmission of HIV, syphilis and hepatitis B virus*, additional HR GE CE issues may be identified that may not be directly contemplated by the tool. These issues are no less important and may be incorporated into and considered in the process of assessment. However, the validation review is not a substitute for a comprehensive and ongoing human rights, gender equality and community engagement monitoring and evaluation process, which is normative and beyond the scope of validation for elimination of vertical transmission.
Step 3: Gathering key documents and stakeholder information

In some cases, law, policy and standard operating procedures that guide specific interventions may not align with what is happening in the programmes or what women are experiencing when they seek or use health services. Examining laws, regulations or policy alone is not enough to determine whether the programme meets human rights standards and ensures gender equality. Understanding how these laws are practised allows for the identification of rights concerns and gaps in implementation, and helps a country make progress to address these issues.

The assessment process must understand both existing laws, regulations and policy AND what is happening in practice.

Examining laws, regulations and policies

The first step to ensure that current sexual and reproductive health care, maternal health care and prevention of vertical transmission efforts comply with validation requirements is to examine the relevant:

- laws (for example, national health care laws, criminal laws, gender equality non-discrimination laws)
- regulations (for example, Ministry of Health rules)
- policies (for example, informed consent procedures).

A desk review should be conducted to gather information and evidence in response to the specific questions outlined in this tool. It should include a review of:

- national constitutions
- HIV laws, health care laws, criminal codes, patients’ rights charters and other relevant laws
- judgments from international, regional and national courts
- country reports to human rights bodies, such as the Committee on the Elimination of Discrimination Against Women (CEDAW), the Committee on Economic, Social and Cultural Rights (CESCR) and the Human Rights Committee (HRC)
- shadow reports submitted to the treaty-monitoring bodies by nongovernmental organizations
- shadow reports submitted to the validation process
- grey literature, including relevant reports from civil society
- concluding observations and recommendations from national human rights institutions and other relevant bodies.
- national programme policies and standards of care
- health care system circulars, training updates
- Global AIDS Monitoring and the country’s National Commitments and Policy Instrument (NCPI).

This list is not exhaustive. Each of the sections in Annex G offers specific suggestions for sources of relevant data.
Examining practice and the lived experiences of women

Women who use prevention of vertical transmission services are uniquely positioned to provide valuable insight into their experiences. This information is essential to determine the extent to which human rights, gender equality and community engagement standards are met in practice.

The tools may include:

- consultations and focus group discussions with and led by women living with HIV and HBV, and women who access antenatal care (ANC) services, including women from key populations and groups in situations of vulnerability or marginalization;
- stakeholder interviews with:
  - key national and local government officials, including from the Ministry of Health and ministries for women, children and gender equality, as well as officials with human rights, gender equality and community engagement functions, for example, the human rights desk at the Ministry of Health, ombudsperson, bureau of gender affairs and others;
  - HIV and vertical transmission programme managers and health service providers, including nurses and midwives; and
  - civil society organizations (CSOs), including organizations of and advocates for women living with HIV, young people living with HIV and women’s groups.
- Independent reports can also be a valuable tool for the NVC to gain information about specific aspects of human rights, gender equality and community engagement practices. The submission of independent reports after the completion of the initial validation report by the NVC requires a specific and guided process to be fair and transparent. In all cases, the safety and security of human rights advocates must be protected, and they should be supported to provide their submission confidentially.

Step 4: Identify gaps, risks and concerns in law, policy and practice through a collaborative multi-stakeholder consultation

The data collection tool may be completed by many different stakeholders engaged in the process, and thus requires the NVC to synthesize findings. To do so, it is recommended to conduct a multi-stakeholder consultation with key stakeholders from the community.

Importantly, throughout the validation process, there must be sufficient opportunities for networks of women with HIV and HBV, civil society and human rights groups to engage directly with the NVC.

The multi-stakeholder consultation should aim to address each of the 10 topics in the assessment tool. For each topic, the discussion should help examine both policy and practice, together aiming to answer three overarching questions:

- Do the programmes and interventions respect, promote and fulfil human rights?
- Do the programmes and interventions meaningfully engage women with HIV, syphilis or HBV?
- Do the programmes and interventions promote gender equality?
As you review the responses to the questions, you should seek to:

- identify gaps in policy and law;
  - Are the laws or policies identified in the assessment in place and operational?
  - Does the substance of the policy reflect and meet the goals outlined in the purpose – for example, to protect confidentiality?
  - Are there any conflicts in policy and law?
- identify gaps and risks in practice;
  - Have communities identified any concerns?
  - Are there monitoring reports from NGOs or reports submitted to CEDAW or other treaty bodies that identify any human rights concerns, relevant challenges with gender equality or challenges for communities seeking to self-organize or participate in national policy spaces?
  - Do the Ministry of Health or programmes to prevent vertical transmission monitor and seek feedback from service users? What does that feedback show about the experience of women accessing services?
  - In assessing the available information, have you identified any gaps in policy or practice which are resulting in human rights problems?
- identify efforts to respond to or remedy these human rights concerns;
- understand whether there are any additional human rights, gender equality or community engagement issues in policy or raised by communities that do not fall into one of the 10 topics outlined in the tool; and
- understand how those additional concerns have been addressed.

The NVC should seek to portray the answers to the above questions in the initial validation report.

The Regional Validation Committee (RVC), in the course of validating the initial report by the NVC and considering their recommendation for validation, may also consider the following questions:

- Is additional information required to understand the policy or practice?
- Do any of the gaps affect the recommendation to validate for elimination?
- What are the proposed recommendations for the country to respond to the gaps or human rights, gender equality or community engagement issues?

Frequently Asked Questions

What are the circumstances that could pose a risk to validation of elimination of vertical transmission in the area of HR GE CE?

“Red flags” when assessing a country’s eligibility for validation include if the country:

- criminalizes HIV or syphilis exposure and transmission;
- mandates testing or treatment of HIV, syphilis or HBV;
- does not have a law, policy or regulation that protects patient confidentiality and confidentiality around HIV status;
- does not have informed consent policies or evidence of lack of informed consent in practice in prevention of vertical transmission or maternal health settings;
- has recent reports of coercive or forced sterilization, contraception, abortion or forced caesarean section that have occurred within the last three years or that remain unaddressed in policy;
• has recent reports of human rights violations within prevention of vertical transmission or related health care settings;
• does not have a mechanism for reporting rights violations, accountability and remedies for violations of human rights;
• does not have a policy addressing gender-based violence in health care settings;
• has policy, regulatory restrictions or restrictive practices that limit access to family planning or sexual and reproductive health services; and
• does not have a mechanism for community engagement.

A country may have a “red flag” or not fully meet a requirement and still be eligible for validation if they demonstrate efforts or progress to resolve the issues. For example, the RVC and the Global Validation Advisory Committee (GVAC) might wish to recommend the country for validation with specific recommendations to make progress in the HR GE CE area.

**What to do if human rights violations are identified during the validation assessment?**

Where human rights violations are identified by individuals or organizations within the validation assessment process, the individual concerned should be supported with information on reporting complaints or receiving redressal and provided contact information of HR groups and CSOs that can provide assistance. Strict confidentiality should be adhered to in the interview process.

**Only one or two people identified a human rights violation. Is it necessary to include it in the report?**

Research or analysis based on peoples’ experiences of the health system is a key part of the assessment, and all reported rights violations must be taken seriously for a deeper understanding of the situation and whether there has been any attempt to remedy it. Even one report of a human rights violation is worthy of further attention, investigation and consideration and should be properly handled within the country’s existing reporting and redressal systems.

For the validation report, information on violations reported to national or other systems and how these have been dealt with should be time-bound to the period of assessment for validation. The RVC and GVAC may take the view that even one report of a human rights violation during the period of assessment could indicate that more individuals utilizing the services are experiencing similar rights violations, and they will seek to understand whether the issue is widespread or systemic.

Questions which the RVC and GVAC will consider, and which should be addressed in the initial validation report, include:

- Is the health care system currently aware of this problem?
- What steps have been taken to eliminate the practice and to ensure effective remedy to the individuals affected?
- How has the community been involved in responding to the problem?
- What remedy does the community seek?
What to do if we discover human rights concerns that have occurred outside the validation assessment time period?

If human rights concerns occurred outside the validation assessment time period, the issue is still worthy of further attention, investigation and consideration. As some of the material from human rights treaty body mechanisms may be more than five years old due to longer reporting cycles, it would be important for the NVC to go back to the most recent CEDAW report and follow up on its recommendation under HIV/right to health.

Sharing examples of the Ministry of Health’s steps to realize its duty to respect, protect and fulfil human rights, gender equality and community engagement can support the analysis. Although experiences from before the period of validation review can be informative and the women should still be connected to redressal options, the focus for determining eligibility for validation remains on the current systems and recent experiences within the programmes.

How can we measure progress?

Progress in the response to the gaps identified through the assessment process can be measured via practical progress commitment from the country to make needed reforms, including a timeline, with specific steps articulated.

Key questions to understand progress include:

- Has the action plan to address the rights violations been developed jointly with impacted communities and other human rights experts?
- Has the Ministry of Health or other duty bearers demonstrated commitment to making the reforms?
- Have the interventions achieved demonstrated shifts in policy or law or demonstrated shifts in practice?

**Step 5: After the analysis and report**

Once the NVC has completed the analysis following the multi-stakeholder consultation and prepared the initial validation report, the RVC and GVAC may follow up on identified areas where there are gaps in policy or practice and propose recommendations for improvement.
TOPIC-BY-TOPIC: UNDERSTANDING THE REQUIREMENTS

Topic 1: Ending criminalization of HIV, syphilis and HBV

Context
A growing global consensus backed by empirical studies confirms that the criminalization of exposure and transmission of HIV, syphilis and HBV is ineffective, discriminatory, runs counter to public health goals and is doing more harm than good. Fear of prosecution discourages the demand for HIV testing, interferes with adherence to treatment and does not support efforts to prevent new HIV infections. An effective, sustainable epidemic response that is consistent with human rights obligations does not criminalize any aspect of vertical transmission of HIV, syphilis and HBV.

Purpose
This section seeks to understand if there are any laws that criminalize or punish people for not disclosing their status, or potentially exposing others to, or transmission of, HIV, syphilis or HBV, and whether there have been any arrests, prosecutions or other forms of punishment on this basis.

Suggested sources for analysis
- National criminal laws or codes
- National health care laws or HIV laws and regulations
- Reports from the Ministry of Justice, prosecution office or other law enforcement authorities
- Reports from community-led monitoring processes
- Reports from civil society and networks of women living with HIV and/or other health advocates
- UNAIDS Global AIDS Reporting on National Commitments and Policy Instrument (NCPI)

Guidance For Analysis
If a country has any law or regulation that explicitly provides for criminalization of HIV, syphilis or HBV and/or if there have been increasing arrests, prosecution or sentencing of people based on these laws in the past three years, that country’s eligibility for validation or maintenance will remain at risk until progress can be demonstrated to ensure that the law has been repealed or amended. Criminal liability for transmission of HIV, syphilis or HBV under existing criminal law must be restricted to exceptional circumstances where a person acts with specific intent to transmit HIV syphilis or HBV and actually does so. Information must be obtained from communities of women who use services to prevent vertical transmission, including networks of women living with HIV and HBV, to establish that exposure, non-disclosure or transmission of HIV, syphilis or HBV is not criminalized or otherwise punished in practice.
**References and further reading**

- [UN ESCR general comment No 22 (2016) on the right to sexual and reproductive health](https://www.who.int/publications/i/item/WHO-FWC-GER-17.4) (accessed 13 July 2023).

**Topic 2: Ensuring voluntary testing and treatment**

**Context**

Voluntary HIV, syphilis and HBV testing and treatment is the foundation of a rights-based and people-centred approach to prevention of vertical transmission. Mandatory, compulsory or testing and treatment that are either conducted without the person’s informed consent or coerced in exchange for access to other services or benefits violate the human right to bodily integrity. There is no public health justification for compulsory testing. Programs that utilize routine provider-initiated testing must include an opt-out policy for testing and must still obtain informed consent. Voluntary testing accompanied by pre- and postcounselling is most effective in reaching public health goals, including adherence to treatment.

WHO recommendations and good practice statements for creating an enabling environment for HIV testing services include:

- HIV testing must be voluntary. All people being tested should be made aware of their right to refuse testing, and they must give informed verbal consent to be tested. Mandatory or coercive HIV testing is never appropriate.
- Countries are encouraged to examine their age-of-consent policies and consider revising them to reduce age-related barriers to HIV services and to empower providers to act in the best interest of the adolescent.

**Purpose**

This section seeks to understand whether testing and treatment for HIV, syphilis and HBV is voluntary. This means that all women are given the information they need to make an autonomous choice, including on any risks, benefits and alternatives, and they are provided with an option to decline the test or treatment without consequences.
Suggested sources for analysis

- National laws including health, labour, travel and immigration laws
- Ministry of Health policies and training curricula on HIV, syphilis and HBV
- Data from community feedback mechanisms or community-led monitoring processes
- Reports from networks of women living with HIV and/or other health advocates
- Interviews with service providers and women using the services
- UNAIDS Global AIDS Reporting on National Commitments and Policy Instrument (NCPI)

Guidance for analysis

If a country has any law or policy that calls for mandatory testing or treatment for HIV, syphilis or HBV for any population, that country’s eligibility for validation or maintenance will remain at risk until progress can be demonstrated to ensure that the policy or law has been revised. While the laws and policies may prohibit mandatory testing or treatment, if there are any reports of people routinely experiencing compulsory testing or treatment, the country should not be validated until measures have been taken to ensure that testing and treatment is voluntary and that women are counselled on the benefits of testing and treatment and informed that they have the right to opt out. Information must be obtained from communities of women who use services to prevent vertical transmission, including networks of women living with HIV, to establish if this is the practice.

References and further reading


Topic 3: Ensuring prior, voluntary and informed consent

Context

All women, indeed all people, have a right to informed consent for any and all medical interventions, including for testing, treatment, family planning, and maternal health interventions. Informed consent is a legal, ethical and professional requirement grounded in the rights to bodily autonomy, privacy and health. Obtaining informed consent supports people-centred care. Involvement in decision-making by obtaining informed consent has documented benefits for the well-being of individuals. Securing informed consent has specific requirements, including capacity – the provision of “adequate and understandable information in a form and language understood by the patient.” Women must be informed fully about the risks and benefits of any/all procedures or tests and any alternatives available to them. They must be given adequate time to consider this information and informed that they have the right to refuse any test or treatment without fear of ill treatment, stigma or retribution from health care providers. Women’s bodily autonomy must be respected in all decision-making, including discussions of family planning options, birth options and choices, and infant testing and feeding options.

Purpose

This section seeks to understand whether women’s prior, voluntary and informed consent to any medical procedure or intervention is a requirement provided for in law and policy and whether, in practice, women are routinely asked for their prior, voluntary and informed consent before any medical procedure or intervention is undertaken.
Suggested sources for analysis

- National laws or regulations such as health care laws or HIV laws which require informed consent
- Ministry of Health or programme level policy requiring informed, voluntary consent
- Patient’s rights laws or charters
- Data from community feedback mechanisms or community-led monitoring processes
- Reports from networks of women living with HIV and/or other health advocates
- Interviews with service providers and women using the services
- UNAIDS Global AIDS Reporting on National Commitments and Policy Instrument (NCPI)

Guidance for analysis

To meet the requirement for validation, the country must have policies and procedures that require health care providers to obtain prior, voluntary and informed consent, including for testing, treatment and any medical procedures or interventions. The informed consent policy must specifically provide for elements of informed consent as outlined above. Information must be obtained from communities of women who use services to prevent vertical transmission, including women living with HIV, to establish if this is the practice.

References and further reading

Topic 4: Eliminating coercive practices, including involuntary sterilization, contraception or abortion

Context
All women, including those living with HIV and HBV, have rights to bodily integrity, to decide whether or not to found a family and to choose the number and timing of their children. As such, women living with HIV and HBV, including women from key and other vulnerable populations, must be able to freely choose from the available contraceptive options autonomously and without coercion. Coercive or forcible practices include mandatory contraception for any population (for example, migrant women), or recommendations, advice or requirements for abortion based on HIV or status or key population membership status, or forced or coerced sterilization. These all constitute violations of women’s human rights. Sterilization may be coerced or compelled in exchange for incentives such as loans, cash payments, access to nutrition or other services or supports, or denial of these services. Sterilization may be a result of persuasion via unequal power dynamics, misinformation, or exaggeration of the risks of HIV transmission, or it may occur during labour or childbirth or as a result of abuse or discrimination. These constitute recognized forms of unlawful coercion and represent violations of human rights. The United Nations High Commission for Human Rights and UNAIDS have also highlighted concerns about forcible and coercive measures to prevent vertical transmission and in particular the counterproductive outcome of coercive measures in meeting public health goals.

The International Federation of Gynecology and Obstetrics Female contraceptive sterilization guidelines set out international best practices to ensure women’s autonomy and informed consent and include clarity that “No woman may be sterilised without her own, previously-given informed consent, with no coercion, pressure, or undue inducement by healthcare providers or institutions.” Further, the guidelines are clear that a woman’s “informed decision must be respected, even if it is considered liable to be harmful to her health.” FIGO guidelines also make clear that consent should not be a condition for access to any treatment, care, support, benefit or “when women may be vulnerable, such as when requesting termination of pregnancy, going into labour or in the aftermath of delivery.”

Purpose
This section seeks to understand whether women experience force or coercion (through pressure or incentives) to undertake involuntary sterilization, contraception, abortion or other interventions such as caesarean section.

Suggested sources for analysis
- National laws
- Ministry of Health policy and procedures
- National human rights institutional reports
- Data from community feedback mechanisms or community-led monitoring processes
- Reports from networks of women living with HIV and/or other health advocates
- Interviews with service providers and women using the services
- Stigma Index Reports and other CSO reports
Guidance for analysis

To meet the requirement for validation, the country must have laws and/or policies in place that prohibit forcible or coercive practices regarding contraception, sterilization and abortion and reflect international standards on elective caesarean section. If there are any reports in the past three years of forced or coerced sterilization, contraception, abortion or other interventions such as caesarean section among women with HIV, syphilis or HBV, the country will not be eligible for validation. Reports of forcible or coercive practices even from a single woman must be investigated, and the country must demonstrate that measures have been instituted to ensure accountability and to stop the practice. Women who may have experienced these human rights violations must have access to justice and remedy. Information must be obtained from communities of women who use services to prevent vertical transmission, including networks of women living with HIV, to establish if this is the practice.

References and further reading

Topic 5: Ensuring confidentiality of health information

Context
All people have a right to confidentiality and privacy when it comes to information about their health. In the context of women living with HIV, ensuring confidentiality and privacy regarding HIV status is a critical tool to reduce stigma and discrimination and to support women to mitigate and manage risks of violence in their lives. Additionally, protecting the confidentiality and privacy of all clients in the antenatal care setting builds trust and supports women to feel safe and comfortable accessing prevention of vertical transmission services, and it supports treatment adherence. Privacy is both a legal and an ethical concept. The legal concept refers to the legal protection that has been accorded to an individual to control both access to and use of personal information. Privacy provides the overall framework within which both confidentiality and security are implemented. Privacy protections vary between jurisdictions and are defined by law and regulations.

Purpose
This section seeks to understand the policies, practices, systems and training that ensure that information about patients (including women with HIV, syphilis or HBV) is kept private and confidential.

Suggested sources for analysis
- National law requiring confidentiality or protecting HIV status from disclosure by health care providers and others
- Ministry of Health or programme level policy providing for confidentiality of HIV status and/or for protections of privacy
- Ministry of Health confidentiality and privacy training curricula
- Data from community feedback mechanisms or community-led monitoring processes
- Reports from networks of women living with HIV and/or other health advocates
- Interviews with service providers and women using the services

Guidance for analysis
To meet the requirements for validation, a country must have policies, procedures, systems and training in place for health care providers to ensure patients’ privacy and confidentiality. These protections must be applied to all patients, including women with HIV, syphilis or HBV or women from key or vulnerable populations, including migrant women and women in prison and other closed settings. Any reports of violations of this right should be investigated and the country must demonstrate that measures have been instituted to improve confidentiality and privacy practices and ensure accountability for breaches of confidentiality and privacy. Women who may have experienced a violation of their right to privacy must have access to justice and remedy. Information must be obtained from communities of women who use services to prevent vertical transmission, including networks of women living with HIV, to establish if practices are in place to ensure patients’ privacy and confidentiality.

References and further reading
- Article 17 of the International Covenant on Civil and Political Rights.
Topic 6: Ensuring equality and non-discrimination

Context
Discrimination can have particularly profound effects on efforts to eliminate the vertical transmission of HIV, syphilis and HBV. Women who have faced discrimination or who perceive or expect stigma in health care settings may be less likely to access prenatal and postnatal treatment and care. Where they do access such care, they may be deterred from using prevention of vertical transmission services. Discrimination is a human rights violation prohibited by international human rights law and most national constitutions. It exacerbates risks and deprives people of their rights and entitlements, fuelling the HIV, syphilis and HBV epidemics.

Purpose
This section seeks to understand if all women can access health care, including sexual and reproductive health services, equally and without any discrimination, including those from key populations, no matter their race/ethnicity, age, HIV or health status, marital status, sexual orientation, gender identity, religion, economic status and other status, such as disability or national origin.

Suggested sources for analysis
- National laws, including the constitution, civil code, and health care, HIV and gender equality laws
- Ministry of Health or programme level policy and training curricula on non-discrimination and equality
-Patient’s Rights Charter
- Data from community feedback mechanisms or community-led monitoring processes
- Reports from networks of women living with HIV and/or NGO’s and health advocates
- Interviews with service providers and women using the services
- UNAIDS Global AIDS Reporting on National Commitments and Policy Instrument (NCPI)

Guidance for analysis
To meet the requirement for validation, the country must have laws, policies and procedures in place that guarantee that all women have equal and non-discriminatory access to health care services, including sexual and reproductive health care. Supporting information to establish equal and non-discriminatory practice must be obtained from communities of women who use services to prevent vertical transmission, including networks of women living with HIV and HBV.

References and further reading
Topic 7: Ensuring accessibility and quality of women-centred health care services

Context

Why AAAQ: Available (includes affordable), accessible, acceptable and good-quality health care are core components of promoting and protecting people’s right to health. The right to the highest attainable standard of health requires that these four attributes be achieved for all people regardless of gender, religion, immigration status, race, ethnicity and without discrimination – particularly relevant to the HIV response for people from key populations. Strategies are needed across health system building blocks to improve the availability (including affordability), accessibility, acceptability, uptake, equitable coverage, quality, effectiveness and efficiency of services for women living with HIV and HBV. If left unaddressed, such barriers undermine health interventions and the sexual and reproductive health and rights (SRHR) of women living with HIV and HBV.

Purpose

This section seeks to understand whether good-quality health services – including SRH services, prevention of vertical transmission and maternal health care – are available, accessible, acceptable, and affordable for all women, and what strategies are in place to address challenges and remove barriers.

Suggested sources for analysis

- Policies on access to prevention of vertical transmission services for vulnerable people
- Ministry of Health training guide, content and schedule
- Ministry of Health or programme level policy providing for aspects of AAAQ
- Stigma Index Reports and other CSO reports
- Data from community feedback mechanisms or community-led monitoring processes
- Reports from networks of women living with HIV and/or NGOs and health advocates
- Interviews with service providers and women using the services

Guidance for analysis

For a country to be validated, it must demonstrate that strategies to improve the availability (including affordability), accessibility, acceptability, uptake, equitable coverage, quality, effectiveness and efficiency of services for all women are in place across the health system. Communities of women who use services to prevent vertical transmission, including networks of women living with HIV and HBV, must verify accessibility and quality of services.

References and further reading

**Topic 8: Addressing gender-based violence**

**Context**
Progress in reducing the prevalence of intimate partner violence against women is important, as an outcome itself and as a proxy for gender inequality. Gender-based violence impacts women’s ability to access and be retained in care for HIV, syphilis and HBV. Fear of intimate partner violence may deter women from disclosing their serostatus or seeking treatment. In the context of prevention of vertical transmission of HIV, interpersonal violence against women is both a contributing factor for HIV acquisition and a consequence of infection. Ending all forms of violence against women and girls is among the core commitments for ending the AIDS epidemic by 2030. WHO observes that "Policies and programmes addressing gender inequality and gender-based violence will help achieve universal targets for HIV prevention, treatment and care. Investment in responses in these areas is an essential part of HIV programming.”

**Purpose**
This section seeks to understand the laws, policies and services available to prevent and respond to gender-based violence and how they are integrated into programmes to prevent vertical transmission.

**Suggested sources for analysis**
- National HIV plan
- Ministry of Health policies
- National laws or plans on gender-based violence
- Data from community feedback mechanisms or community-led monitoring processes
- Reports from networks of women living with HIV and/or NGOs and health advocates
- Interviews with service providers and women using the services
- National statistics, including Demographic and Health Survey (DHS)

**Guidance for analysis**
To comply with this requirement, policies and procedures must be in place which respond to gender-based violence and make adequate provision for training and sensitization of health care providers, police and judiciary, and for support and safety planning for women. Information must be obtained from communities of women who use services to prevent vertical transmission, including networks of women living with HIV, to establish that these supports are available.

**References and further reading**
Topic 9: Engaging and being accountable to communities

Context
The global consensus is that community engagement of people living with HIV has many benefits and is essential to the success of the HIV response. There are now many examples of effective strategies to involve community in the policy-making process, programme development and implementation, advocacy and community-led service delivery. Engagement and participation of women living with HIV and HBV and women affected by syphilis – in particular, in the formulation of health laws, policies, programmes, and monitoring and evaluation (M&E) systems that affect them – ensure better, more effective programming. Engagement and participation of affected communities of women living with HIV ensure that they get treatment to keep themselves well and their children free from HIV and syphilis. Community engagement is central to improving quality of care. The perspectives of women, their families and communities on the quality of services influence their decisions to seek care. Engagement of facility service providers with the communities they serve – so that they can understand their expectations, build trust and engage them in the process of delivery – is an essential component for creating demand for and access to quality maternal and newborn services.

WHO Community Engagement Framework
Definition of community engagement for quality, integrated, people-centred and resilient health services: Community engagement is a process of developing relationships that enable stakeholders to work together to address health-related issues and promote well-being to achieve positive health impact and outcomes.”

Purpose
This section seeks to understand how communities – in particular, groups representing women using the services to prevent vertical transmission – are meaningfully involved in the planning, implementation and monitoring of both policies and programmes.

Suggested sources for analysis
- National HIV plan
- Ministry of Health policies
- Data from community feedback mechanisms or community-led monitoring processes
- Reports from networks of women living with HIV and/or NGOs and health advocates

Guidance for analysis
To comply with the requirement of community engagement, countries must demonstrate that they have strategies in place to engage women with HIV, syphilis or HBV meaningfully (including women from key populations) in planning, implementation, monitoring and gathering evidence of engagement that has changed policy and practice, if available. For example, does the government support and fund any community-led monitoring process, engage women in decision-making spaces such as technical working groups, or provide support for research or advocacy led by women’s groups. Information must be obtained from communities of women who use services to prevent vertical transmission, including networks of women living with HIV and HBV, to establish implementation of these practices and their effectiveness.

References and further reading

- Stronger together: From health and community systems to systems for health (accessed 6 August 2023).

Topic 10: Ensuring access to justice

Context
States have an obligation to guarantee all persons their rights to access justice and to ensure that when people’s human rights are violated, including sexual and reproductive rights, they can achieve meaningful and effective remedy. States must ensure that violations of human rights are investigated and that the perpetrators of rights violations are held accountable. Appropriate remedies “include, but are not limited to, adequate, effective and prompt reparation in the form of restitution, compensation, rehabilitation, satisfaction and guarantees of non-repetition.”

Access to justice includes not only access to the courts or legal representation, but also the ability to report violations and access informal, non-state justice mechanisms. Ministries of Health should seek to empower individuals and communities to assert their rights and promote accountability, as well as promoting an enabling environment that facilitates individuals’ access to agencies or organizations for reporting rights violations, and a health care system that takes action to correct the causes of rights violations.

Purpose
This section seeks to understand the availability, accessibility and effectiveness of mechanisms or places for women to report and/or press claims for rights violations in health care settings, and obtain timely and effective remedies that provide adequate redress for violations, prevent their continuation and prevent violations in the future.

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Suggested sources for analysis

- National laws, including laws covering health care and HIV, civil codes, criminal and human or civil rights laws
- Ministry of Health policies and procedures
- National human rights reports
- Data from community feedback mechanisms or community-led monitoring processes
- Reports from networks of women living with HIV and/or NGOs and health advocates
- UNAIDS Global AIDS Reporting on National Commitments and Policy Instrument (NCPI)

Guidance for analysis

To comply with this requirement, the country must demonstrate an accessible and working mechanism where women can safely file complaints about violations of their rights, through which the complaints will be heard and investigated and women can access remedy or redress, and that hold service providers accountable. Communities of women who use services to prevent vertical transmission, including networks of women living with HIV, must verify that these mechanisms are accessible and effective.

References and further reading

- UN ESCR general comment No 22 (2016) on the right to sexual and reproductive health (accessed 13 July 2023).
# ASSESSMENT QUESTIONS

## Topic 1: Ending criminalization of HIV, syphilis and HBV

<table>
<thead>
<tr>
<th>Questions</th>
<th>Responses</th>
<th>Sources consulted</th>
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</thead>
<tbody>
<tr>
<td>1. Provide details of any laws or regulations during the assessment time period that criminalize or punish people for any of the following:</td>
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<tr>
<td>• exposure to HIV, syphilis or HBV</td>
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<tr>
<td>• non-disclosure of HIV, syphilis or HBV</td>
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<tr>
<td>• transmission of HIV, syphilis or HBV</td>
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<tr>
<td>2. Provide details of any laws or regulations during the assessment time period that provide for increased sentencing or punishment based on HIV, syphilis and HBV status, if any.</td>
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<tr>
<td>3. Provide details of arrest, prosecution or punishment of any women for transmission, exposure to, or non-disclosure of HIV, syphilis or HBV during the assessment time period, if any.</td>
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</tbody>
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## Topic 2: Ensuring voluntary testing and treatment

<table>
<thead>
<tr>
<th>Questions</th>
<th>Responses</th>
<th>Sources consulted</th>
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</thead>
<tbody>
<tr>
<td>1. Provide details of laws and policies in place during the assessment time period that explicitly prohibit mandatory (or compulsory) testing or treatment of pregnant women for HIV, syphilis and HBV? Please share the relevant policy or law.</td>
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<td>2. Is testing or treatment mandatory:</td>
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<tr>
<td>a. during pregnancy?</td>
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<tr>
<td>b. for certain groups of women? (Please specify which groups.)</td>
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<td>c. for certain jobs? (Please specify which ones.)</td>
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<td>d. as a precondition before marriage?</td>
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<td>e. as a precondition for a work, study or resident permit?</td>
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<tr>
<td>3. Provide information on the training of service providers on ensuring voluntary testing or treatment for HIV, syphilis and HBV, if any. Please describe whether the training covers the following aspects:</td>
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<tr>
<td>a. the process of testing or the diagnosis</td>
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<td>b. the available services depending on the results or the proposed treatment</td>
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<td>c. the risks and benefits of testing or treatment</td>
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<td>d. alternative treatments with their risks and benefits</td>
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<td>e. the risks and benefits of declining treatment</td>
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<td>f. the option to refuse testing or treatment without consequences.</td>
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<tr>
<td>4. Provide details of any reports or community feedback regarding mandatory testing or treatment of pregnant women for HIV, syphilis and HBV occurring during the assessment time period, if any.</td>
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</tbody>
</table>
## Topic 3: Ensuring prior, voluntary and informed consent

<table>
<thead>
<tr>
<th>Questions</th>
<th>Responses</th>
<th>Sources consulted</th>
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</thead>
<tbody>
<tr>
<td>1. Provide details on laws and policies in place during the assessment time period that guarantee prior, voluntary and informed consent from women undergoing any medical procedure or intervention?*</td>
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<tr>
<td>*Consider all settings and services, including public and private maternal and child health, family planning, sexual and reproductive health, HIV, etc.</td>
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</table>
| 2. Provide details of policies and standard operating procedures in place during the assessment time period to ensure that the process for obtaining prior, voluntary and informed consent to any medical procedure or intervention includes:  
  a. accurate and unbiased information in an understandable form and language;  
  b. the risks and benefits of any/all procedures or tests and any alternatives available;  
  c. adequate time to consider this information; and  
  d. the right to refuse any test or treatment without retaliation. |           |                  |
| 3. Can adolescents get tested for HIV, syphilis or HBV without prior parental permission?  
  a. If so, at what age?  
  b. Are there any options or circumstances for adolescents below the age defined in national laws and policies to consent on their own? Please provide details. |           |                  |
| 4. Provide details of any reports of violations of informed consent from women, including women from key populations and adolescents, and/or reports of third-party authorization requirements from spouse, partner or parent during the assessment time period, if any. |           |                  |
### Topic 4: Eliminating coercive practices, including involuntary sterilization, contraception or abortion

<table>
<thead>
<tr>
<th>Questions</th>
<th>Responses</th>
<th>Sources consulted</th>
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</thead>
<tbody>
<tr>
<td>1. Provide details on laws and policies in place during the assessment time period regarding the prohibition of coercive practices such as forced, coerced and otherwise involuntary sterilization, contraception and/or abortion, if any.</td>
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<tr>
<td>2. Please describe the policy in place during the assessment time period on elective caesarean section, including its application for women with HIV, syphilis or HBV.</td>
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<tr>
<td>3. Provide details of any reports during the assessment time period of involuntary sterilization, contraception, abortion and/or other medical procedures.</td>
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<tr>
<td>4. If there have been reports of force or coercion during the assessment time period, please describe what measures or interventions have been put in place to prevent ongoing practice and respond to these human rights violations.</td>
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Topic 5: Ensuring confidentiality of health information

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<thead>
<tr>
<th>Questions</th>
<th>Responses</th>
<th>Sources consulted</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Provide details on laws and policies in place during the assessment time period that guarantee the confidentiality and privacy of patients’ information, such as their HIV status, if any.</td>
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<tr>
<td>2. Provide details of the systems for the protection of data privacy and confidentiality and training provided to health care providers on these issues, including around voluntary partner notification.</td>
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<tr>
<td>3. Provide details of any reports from women during the assessment time period of violations of the right to privacy and confidentiality by health care providers, if any.</td>
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</table>
### Topic 6: Ensuring equality and non-discrimination

<table>
<thead>
<tr>
<th>Questions</th>
<th>Responses</th>
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</tr>
</thead>
</table>
| 1. Provide details of laws and policies and relevant legal frameworks in place during the assessment time period that guarantee women’s equal access to health care (including sexual and reproductive health care, prevention of vertical transmission services, and maternal health care) without discrimination. Specifically, provisions that guarantee: | a. gender equality  
b. non-discrimination based on health status, including HIV, syphilis or HBV  
c. non-discrimination based on economic and social status. |                  |
| 2. Are there provisions that guarantee access for these specific populations (that is, the law or policy includes a non-discrimination reference): | a. migrant or trafficked women  
b. refugees  
c. sex workers  
d. women who use drugs  
e. transgender people  
f. lesbian, bisexual or queer women  
g. women in prison/detention centres  
h. adolescent or young women  
i. unmarried women  
j. indigenous women  
k. women from religious or ethnic minorities  
l. women with disabilities |                  |
| 3. Please describe the practices and any other measures in place during the assessment time period to ensure equality and non-discrimination in accessing health care, including training of health care workers. Please provide details of relevant documents, if any. |                                                                 |                  |
| 4. Are there any policies or procedures in place during the assessment time period which require: | a. prior authorization by a male relative/husband for a woman to access sexual and reproductive health care, medical examination or treatment, including access to contraceptives or abortion?  
b. parental authorization for adolescents’ access to sexual and reproductive health care, medical examination or treatment, including access to contraceptives or abortion? |                  |
| 5. Provide details of any community feedback or reports of women with HIV, syphilis or HBV being denied equal access to health care services during the assessment time period. |                                                                 |                  |
# Topic 7: Ensuring accessibility and quality of women-centred health care services

<table>
<thead>
<tr>
<th>Questions</th>
<th>Responses</th>
<th>Sources consulted</th>
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</thead>
<tbody>
<tr>
<td>1. What is the farthest that women have to travel for ANC/PMTCT services?</td>
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<tr>
<td>2. What other health services are integrated in settings offering PMTCT?</td>
<td>a. family planning?</td>
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<td></td>
<td>b. STI prevention &amp; treatment, including for syphilis?</td>
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<td></td>
<td>c. HIV testing and treatment services, including early infant diagnosis?</td>
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<td></td>
<td>d. HBV testing and treatment services?</td>
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<tr>
<td>3. What fees or costs must women pay to access ANC or PMTCT services in the public sector?</td>
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<tr>
<td>4. In facilities offering PMTCT services, have there been stockouts or shortages of medicines or diagnostics (for HIV, syphilis or HBV) during the assessment time period? Please describe.</td>
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<tr>
<td>5. In facilities offering PMTCT services, have there been any shortages of trained health care workers during the assessment time period?</td>
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<tr>
<td>6. What guidance is given to mothers living with HIV on infant feeding options?</td>
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<tr>
<td>7. What birth method is recommended for pregnant women living with HIV?</td>
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<tr>
<td>8. What counselling or psychosocial support is provided for women who test positive for HIV, syphilis or HBV? Please provide details.</td>
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<tr>
<td>9. Please describe any barriers to access for these populations of women and what interventions are in place to support women to access services: a. migrant women b. refugees c. sex workers d. women who use drugs e. transgender people f. lesbian, bisexual or queer women g. women in prison/detention centres h. adolescent or young women i. unmarried women j. indigenous women k. women from religious or ethnic minorities l. women with disabilities.</td>
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<tr>
<td>10. Provide details from any reports of stigma or discrimination during the assessment time period.</td>
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<tr>
<td>11. Please provide details on training of health care workers in human rights issues, including: a. the range of topics covered b. the number of hours of training provided on these topics.</td>
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</tbody>
</table>
## Topic 8: Addressing gender-based violence

<table>
<thead>
<tr>
<th>Questions</th>
<th>Responses</th>
<th>Sources consulted</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Provide details of laws and policies in place during the assessment time period that prohibit and/or provide protection from violence against women and girls, including those from key populations.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Do services to prevent vertical transmission include interventions or have linkages with services for women experiencing violence, such as resources, referrals, safety planning, counselling and care? If so, please describe the available supports and policies.</td>
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<tr>
<td>3. Provide details of trainings of health care providers on gender-based violence during the assessment time period.</td>
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<tr>
<td>4. Provide national plans of action and/or policies for prevention of violence and provision of services and support to survivors of violence against women.</td>
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</table>
# Topic 9: Engaging and being accountable to communities

<table>
<thead>
<tr>
<th>Questions</th>
<th>Responses</th>
<th>Sources consulted</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Does your country have any policies, guidelines or strategies in place during the assessment time period to ensure community engagement, including the meaningful involvement of women living with HIV, syphilis or HBV, in the planning, implementation and monitoring of programmes to prevent vertical transmission?</td>
<td></td>
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<tr>
<td>2. Describe the opportunities for communities of women using services to prevent vertical transmission to be meaningfully involved in the planning, implementation and monitoring of national policies, guidelines and programmes during the assessment time period.</td>
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<tr>
<td>3. Does the annual PMTCT progress report include input and analysis from civil society and communities, including women living with HIV and key populations?</td>
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<tr>
<td>4. Please describe mechanisms in place during the assessment time period for collecting the feedback of women who use services to prevent vertical transmission, including women from key populations, and how this feedback is used to improve the quality of these services.</td>
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**Topic 10: Ensuring access to justice**

<table>
<thead>
<tr>
<th>Questions</th>
<th>Responses</th>
<th>Sources consulted</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Please provide details of mechanisms or fora/processes that are available to women to report human rights abuses and to press claims for rights violations in health care settings. Please describe:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>a. accessibility of the process for women, including affordability and language accessibility;</td>
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<tr>
<td>b. how the process holds service providers accountable for rights violations; and</td>
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<tr>
<td>c. protections in place to prevent and address retaliation against women who report violations.</td>
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<tr>
<td>2. Provide details of any reports of rights violations or claims pressed during the assessment time period (if not addressed in another section). For these reports/claims, provide details on the process of investigation, the remedies available to women and any measures taken to prevent future violations (how service providers were held accountable and any resulting policy changes).</td>
<td></td>
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<tr>
<td>3. Are the available remedies for rights violations in health care settings timely and effective in that they prevent the continuation of the alleged violation and provide adequate redress?</td>
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</tbody>
</table>
For more information, contact:

World Health Organization
Department of HIV/AIDS
20, avenue Appia
1211 Geneva 27
Switzerland

E-mail: hiv-aids@who.int

www.who.int/hiv