## **ANNEX III**

# Terms of Reference (TOR)

#### GLOBAL REVIEW HIV/AIDS TREATMENT ACCESS FOR WOMEN

## I. INTRODUCTION

UN Women's role is to promote integration of gender equality in global and national HIV responses through a human rights-based framework. This global review of women's access to HIV care and treatment aims to explore the gender dimensions of access to understand how structural factors impact women's access to care and treatment, particularly at household and community levels, utilizing the essential elements of the Right to Health per the international human rights framework<sup>1</sup>. In the context of the implementation of new treatment guidelines, the expansion of treatment services, strategic investment framework analysis, this global review, with a specific country level study component, and its recommendations will provide evidence and guidance to support national policy, strategy development and programming.

## II. BACKGROUND

Gender inequality and persistent violations of women's human rights continue to be a key driver of the epidemic. It fuels an increase in infection rates, and reduces the ability of women and girls to cope with the epidemic. Of the 32.1 million adults living with HIV in 2012, 17.7 million were women<sup>2</sup>, this represents an increase of 1 million from 2011 (16.7 million)<sup>3</sup>. Women represent nearly 52 percent of the people living with HIV/AIDS (PLWHA) globally<sup>4</sup>, and young women account for 60 percent of new infections.<sup>5</sup> Among pregnant women who needed antiretroviral therapy for their own health in 2012, 58% received HIV treatment.

In some regions, there is a starker picture which shows that the spread and impact of HIV and AIDS disproportionately affects women and adolescent girls who are socially, culturally, biologically and economically more vulnerable. In Sub-Saharan Africa, women and girls account for 58 percent of Africans living with HIV, and young women aged 15-24 are at least eight times more likely than men to be HIV-positive.<sup>6</sup> Alongside Sub-Saharan Africa, the Caribbean is the only other region where women and girls outnumber men and boys living with HIV; in 2009, an estimated 53 percent of people living with HIV/AIDS were women.<sup>7</sup> In Asia, women too are

<sup>&</sup>lt;sup>1</sup> Office of the United Nations High Commissioner for Human Rights, Technical Guidance on the application of human rights-based approach to implementation of policies and programmes to reduce preventable maternal morbidity and mortality, para. 85, U.N. Doc. A/HRC/21/22 (July 2, 2012).

<sup>&</sup>lt;sup>2</sup> 2013 UNAIDS Global Report Epidemiology Slides

<sup>&</sup>lt;sup>3</sup> November 2012 UNAIDS Core Epidemiology Slides

<sup>&</sup>lt;sup>4</sup> 2013 UNAIDS Global Report Epidemiology Slides.

<sup>&</sup>lt;sup>5</sup> UNICEF, 2011, Opportunity in crisis: Preventing HIV from early adolescence to young adulthood, p. 4.

<sup>&</sup>lt;sup>6</sup> UNAIDS, 2012, Report on the Global AIDS Epidemic, p. 70.

<sup>&</sup>lt;sup>7</sup> WHO, UNICEF and UNAIDS, 2011, Global HIV/AIDS Response: Epidemic Update and Health Sector Progress towards Universal Access—Progress Report 2011.

accounting for a growing proportion of HIV infections overall, up from 21 percent in 1990 to 35 percent in 2009.<sup>8</sup>

HIV epidemic impact on women and girls is intensified by women's physiological susceptibility to HIV and unequal power relations between men and women. Widespread social and economic exclusion makes women more affected by the consequences of HIV in terms of stigma and discrimination, fear, violence and misconceptions about the disease. In most cultures, this exclusion, combined with unequal access to education and resources, restricts the potential for women to access essential services and support.

Though in reviews of recent data of ART access in most regions of the world, and especially in settings with a high burden of HIV infection, women are more likely than men to be accessing ART, this data includes both pregnant women accessing eMTCT and other women accessing services through alternate entry points such as VCT centers, TB clinics and provider initiated testing.<sup>9</sup> It is unclear whether access for women is higher than men simply because eMTCT programs facilitate HIV testing and treatment or whether women living with HIV who do not want or are unable to get pregnant still have more access than men to treatment.<sup>10</sup> In 2012, 68% of pregnant women with HIV-positive test results were subsequently assessed for ART eligibility.<sup>11</sup> Yet, considering women's diminished access to other health services has been well documented, in particular for maternal health services, further analysis is needed.

Currently, little is understood regarding women's access across her lifecycle, in particular, for adolescent girls and women who are not currently pregnant. <sup>12</sup> Some studies have found that equity in access differs by age group: In Malawi, 10,000 people are on treatment, with proportionately more females accessing treatment than men. However, in the 15 to 19 year age group, more men are proportionately on treatment despite the fact that HIV prevalence in this age group is higher among women. There were more women than men on treatment for ages 30 to 39, yet HIV prevalence in this age group is higher in men as compared to women. Key affected populations, such as sex workers and those who use drugs may face many barriers in accessing treatment.

Women are acknowledged to be the heavily affected and infected by HIV globally and disproportionately infected in high prevalence regions and the centrality of gender equality to the HIV response has been recognized at the international level since 2001.<sup>13</sup>

<sup>&</sup>lt;sup>8</sup> UNAIDS, 2010, Report on the Global AIDS Epidemic, p. 35.

<sup>&</sup>lt;sup>9</sup> WHO, UNICEF, UNAIDS. Global Update on HIV Treatment: June 2013

<sup>&</sup>lt;sup>10</sup>Eyakuze et al., 2008

<sup>&</sup>lt;sup>11</sup> WHO, UNICEF, UNAIDS. Global Update on HIV Treatment: June 2013

<sup>&</sup>lt;sup>12</sup>The role of gender inequities in women's access to reproductive health care: a population-level study of Namibia, Kenya, Nepal, and India; <u>Amrita Namasivayam</u>, <u>Donatus C Osuorah</u>, <u>Rahman Syed</u>, and <u>Diddy Antai</u> Int J Womens Health. 2012; 4: 351–364.

<sup>&</sup>lt;sup>13</sup> Key global commitments on HIV/AIDS include the 2001 Declaration of Commitment adopted by 189 Member States at the UN General Assembly Special Session on HIV/AIDS (UNGASS), which specifically outlines gender equality commitments. In 2006, at the five year review of the General Assembly Special Session of 2001, States reaffirmed the commitments made in the 2001, and agreed to setting national targets for 2010 on the provision of prevention, care and treatment (with interim targets for 2008). The 2006 Political Declaration on HIV/AIDS<sup>13</sup> also

Barriers such as cost of medications, lack of food, and child-care responsibilities may discourage women living with HIV from accessing antiretroviral therapy. A study found that patients who were HIV-positive but did not access antiretroviral therapy were twice as likely as patients on antiretroviral therapy to report not having enough food to take with treatment as a concern, in addition to concerns about cost barriers. Another study found that cost of ARVs, with direct out of pocket payment at point of care delivery decreased access to ARVs. Another study found transport costs and waiting time a barrier to access to treatment.<sup>14</sup>

In the wider view of a woman's experience receiving treatment there is an interplay of structural factors which affect women's overall access to health and resources which deserves further examination in order to develop policy, programmatic and budgetary responses and interventions addressing the needs and rights of women.<sup>15</sup>

In light of the the rollout of new treatment guidelines, which include the multiple options for implementation, there is an opportunity to assess how treatment programs are reaching beneficiaries and further focused analysis is needed to understand how factors, including but not limited to, poverty, economic security, decision-making, stigma and discrimination influence treatment access. With the promise of expanded access to treatment through scaled up, it is crucial to understand how barriers women face due to gender inequality impact their access to treatment. When the construct of access is viewed from a gender-responsive and human rights based perspective, availability, affordability, acceptability and quality components can be explored.

### III. JUSTIFICATION AND PURPOSE OF REVIEW

This global review takes place during a turning point in the HIV epidemic where increasing more focus is placed on strategic investments in health based on the specific characteristics of a region or country's epidemic. In parallel, the rollout of new treatment guidelines, which include the multiple options for implementation, offers an opportunity to assess how treatment programs are reaching beneficiaries. The review is intended to inform coordinated efforts of all stakeholders striving to achieve the UNAIDS Getting to Zero strategy.

Global Review Objectives: Overall, the primary objectives of this review are to:

- 1. Increase understanding of the dynamics of ART coverage and access for women globally beyond the current indicators,
- 2. Identify key barriers to HIV care and treatment at household, community and health system levels;

<sup>15</sup> See UNAIDS, 2012, Together We Will End AIDS, p. 70; Report of the Secretary General Report, 2012, United to End AIDS: Achieving the Targets of the 2011 Political Declaration, A/66/757. Refer also to http://www.whatworksforwomen.org/.

further recognized that gender inequalities and all forms of violence against women increase their vulnerability to HIV/AIDS.

<sup>&</sup>lt;sup>14</sup> Gap noted, for example, in Zambia (Fox et al., 2010a); Burkina Faso (Kouanda et al., 2010b); India (Thomas et al., 2009); Mozambique (Posse and Baltussen, 2009); Uganda(Geng et al., 2010b; Tuller et al.,

<sup>2010);</sup> **Zimbabwe** (Skovdal et al., 2011c); **Colombia**(Arrivillaga et al., 2009); **Tanzania** (Wringe et al., 2009 cited in Geng et al., 2010a);**Indonesia** (Riyarto et al., 2010); **sub-Saharan Africa** (Mills et al., 2006).

- 3. Renew discussion on the measurement of treatment accessibility relative to frameworks measuring women's access to broader health services
- 4. Study accessibility barriers in country-level assessments (2-5 countries)
- 5. Develop key findings which inform and provide recommendations for policy and programming.

**Use of Review**: The information and evidence generated by the review will be used by UN, donors, civil society, governments, and other stakeholders to:

- Contribute to the evidence base on effective approaches and strategies for addressing and integrating gender equality and women's rights into national HIV treatment programs;
- Provide nuanced perspective on women's treatment access addressing structural level factors.
- Inform policymakers of the critical barriers to women's treatment access and share strategies and lessons learned.
- Facilitate a process of strategic reflection and learning for UN Women, UN system partners, and donors with respect to effective national and sub-national strategies and approaches for making the AIDS response work better for women.
- Support programming to address structural barriers and constraints to treatment access.
- Provide evidence and guidance to inform new WHO treatment guidelines operationalization.
- Identify key strategies with potential for scale-up

## IV. GLOBAL REVIEW CRITERIA

Conventional measurements of national HIV treatment programs include **coverage** and **access**. Although, this review will focus on measurements of access, the relationship between access and coverage is important as the elements of access will normally determine coverage levels.<sup>16</sup> It is well understood that broadly speaking, coverage measures are utilized to understand the effectiveness and strength of HIV care and treatment programs and the development of sexaggregated coverage data is a critical step for understanding how effective HIV treatment programs are in reaching women on a population-level.<sup>17</sup> However, coverage data is limited in its ability to provide a nuanced assessment of women's access and understanding the specific barriers to their access at other levels.

Access to antiretroviral treatment is defined in terms of availability, affordability, acceptability and quality. A key part of accessibility broadly is access to services without discrimination, both

<sup>&</sup>lt;sup>16</sup> Coverage is defined as the number of individuals receiving ART at a point in time divided by the number of individuals who are eligible to receive treatment at the same point in time (including those who are already receiving ART). This is a cross-sectional measure, a "snapshot" of the cumulative ART enrolment relative to the "backlog" of unmet need, at a point in time. The measure is widely used and is the indicator of ART access that is currently recommended by the United Nations General Assembly Special Session on HIV/AIDS (UNGASS). The current globally agreed definition of cumulative ART coverage has proved an invaluable tool for promoting the systematic estimation of ART coverage at country level.

<sup>&</sup>lt;sup>17</sup> How should access to antiretroviral treatment be measured? Leigh F Johnson & Andrew Boulle: *Bulletin of the World Health Organization* 2011;89:157-160

in law and in practice, as well as physical or geographic access and access to information, which is unbiased, clear and scientifically accurate. *Availability* is defined as an adequate number of functioning health care facilities, services, goods (including commodities) and programs to serve the population. *Affordability* is defined through the principle of equity to ensure that poor patients do not bear a disproportionate burden of health costs. *Acceptability* entails that services be culturally appropriate and take into account the interests and needs of minorities, indigenous populations and age groups. *Quality* is defined as scientifically and medically appropriate services where service providers receive adequate training; there is access to necessary drugs, equipment, safe and potable water and adequate sanitation. Most measures of access do not include all domains. Because of the contextual specificity of these measures, targets must be developed locally (nationally) and they are often not standardized Country targets for availability are usually defined at district level.

Most measures of access utilize service availability mapping and population, household surveys and pilot programs of free services or facility-based surveys as data sources. These methods of measurement often include indicators of the price of an intervention, disposal income of the individual, geographic location of provider in relation to the individual, cultural and social acceptability of an intervention, availability of necessary technology for delivering the intervention (quality), expected health gain from the intervention, performance of provider, adherence of the individual. Most studies of access focus on the primary loci of delivery including the hospital, health center, community or home. The limitations of current accessibility measures stem from their focus on health system service delivery and are unable to address the critical points of intersection within the gendered experiences of women. There are social, cultural, economic, and environmental factors that come to bear in terms of access to treatment for women (i.e. women's access to economic resources, or decision-making power within households, gendered division of labor in household, discrimination/stigma in communities and society, violence, etc.). Health system-based and cost-effectiveness measures do not capture these aspects.

Conceptually, access domains address the intersection of human rights and health needs comprehensively, however current measures in practice are limited in scope, particularly in their analysis of factors at the household and community-levels.

This review aims to broaden the conventional understanding of indicators of access to understand other perspectives and underlying causes of barriers to access, particularly at the household and community levels. This would include recommended possible new dimensions and measures of access for consideration as well as identification and highlighting of strategies currently being tested to address structural factors.

#### **Illustrative Questions:**

These are illustrative questions. It is expected that the review team will revise the overall analytical framework and refine the review questions during Phase I.

#### **Key Questions:**

- i. What is the big picture of treatment access for women by age, geographic region, pregnancy status, eligibility, etc.?
- ii. How does stigma affect ART access?
- iii. What is the role of discrimination (legal, customary) in restricting access?
- iv. With regards to women's access to resources and decision-making, what is the effect on HIV/AIDS treatment access?
- v. How does access to information and education affect access to HIV/AIDS treatment?
- vi. How are cultural norms and socially determined roles influencing women's access to HIV/AIDS treatment?
- vii. What specific barriers do women face accessing treatment: focused on treatment for women's own health vs. PMTCT? (including structural factors)
  - a. What barriers exist at the individual level?
  - b. What barriers exist at the household level?
  - c. What barriers exist at the community level?
  - d. What barriers exist at the national/societal level?
- viii. Are specific rights violations preventing women from seeking health care in relation to HIV? Including individual and structural factors for low uptake among women (i.e. risks of violence, threats of forced sterilization, fear of abandonment, divorce, coerced sharing of drugs, etc.)?

### V. REVIEW APPROACH AND METHODOLOGY:

UN Women will contract a highly respected research entity through a competitive process to complete the review. The review will be carried out using a number of research techniques. A literature review and meta-analysis of existing information is required. *Bidders are encouraged to offer creative and innovative approaches that are cost effective and time efficient*.

Since the study questions are multifaceted it is expected that there will be multiple data sources. These may include:

- Existing national HIV/AIDS programme and country-level data (DHIS)
- Key informant interviews with key stakeholders
- Small scale specific further study in critical areas of exploration.
- National Database/sex disaggregation of treatment data/health facility data/GIS mapping

The four phases of the review are:

#### Phase I. Systematic Review:

- Meet with UN Women HIV team
- Draft an Inception Report with final methodology for review by the Advisory Group.
- Refine the systematic review methodology/question matrix based on Global Advisory Group feedback.
- Conduct literature search and analysis of existing data
- Prepare preliminary findings report for presentation at Experts' meeting.
- Prepare proposals for small scale country studies identifying relevant databases

(if relevant), specific countries and methodology.
Phase II. Expert Meeting:
Plan expert meeting in collaboration with UN Women.
Present Preliminary Findings to advisory group and experts
Facilitate refinement of recommendations
• Present proposed small scale studies to advisory group for feedback
• Finalize plans for small scale studies
Phase III: Country Study execution
• Undertake country visits;
Conduct small scale studies
Prepare study reports including findings
Phase IV. Analysis and Report Writing
• Review and analyze all available data;
• Prepare and submit a first draft of the synthesis review report to Global
Advisory Group for comments;
• Deliver a PowerPoint Presentation of key findings, lessons learned, and
recommendations to global advisory group.
Revise report based on feedback of Global Advisory Group
• Submit final report including outlines for proposed publications.
Deliver PowerPoint presentation of key findings for each country study.

#### Additional Considerations:

**Ethics Approvals**: Dependent on the methodology proposed and agreed upon for the countrylevel studies, ethical approval must be obtained prior to initiation of data collection with appropriate national and international bodies. This will be determined in consultation with the UN Women research and data section as well key country-level authorities.

**Local partnerships**: The inclusion of local partners for implementation of country-level studies is a priority throughout the full cycle of the studies. A key factor in developing small-scale studies will be the potential local partners to take active roles in the implementation, analysis, and dissemination of findings. UN Women will provide support for partnership development with national government counterparts, community stakeholders and local research entities.

#### VI. MANAGEMENT OF THE GLOBAL REVIEW PROCESS

The review will be managed by the UN Women HIV and Health Team in the Governance and Leadership Section in Policy Division and will also be guided by an **Advisory Group**.

#### The global advisory group will:

• Provide guidance to the implementing partner on the overall thematic area through quarterly teleconference meetings.

- Provide technical inputs to the a) inception report/review methodology, b) preliminary review findings, and c) final report.
- Attend and actively collaborate in the experts' group meeting to define areas and locations for additional surveys and data analysis and development of recommendations.
- Provide consultative advice regarding specific technical areas of expertise relevant to the review and studies.
- Support the launching of the review and the dissemination of the findings and recommendations globally.

## VII. EXPECTED PRODUCTS AND TIMELINE

The global review will be carried out from **June 2014 to September 2014**. All deliverables will be in English and submitted to the Programme Specialist.

- A review framework document which includes the agreed on review methodology, revised review question matrix, data collection tools and analysis methods, and work plan (with corresponding timeline). The framework document will also identify list of information sources, including key stakeholders.
- **Preliminary Literature Review findings report:** For presentation at the Experts' meeting
- Expert Meeting Report
- **Power point presentation(s)** to each country at the close of each field visit. Presentations will outline preliminary findings, lessons learned, good practices and recommendations to key stakeholders.
- Summaries: 1-3 page summary sheets for the global review and for each study for external dissemination.
- First Draft Review Report; which contains country profiles,
- **PowerPoint Presentation** to global advisory group, and national partners on main findings/recommendations and proposed dissemination strategy; and,
- Global Review Report

## VIII. REVIEW TEAM COMPOSITION, QUALIFICATIONS AND SKILLS

The global review will be conducted by an independent review team of at least three experts. The Team Leader and Team members should have the requisite and complementary skills set (individually and jointly) to undertake a complex, multi-country end-of-programme review. Consideration should be given to partnering/collaborating with in-country consultants.

**The Review Team Leader** will demonstrate experience and expertise in leading and managing large programme reviews. S/he will be responsible for coordinating the global review as a whole; including internal review team coordination and logistics, preparation of the work plan, dissemination of all methodological tools, delivery of the expected review outputs and all presentations. Specifically, the **Review Team Leader** is expected to bring the following expertise:

- At least a master's degree, PhD preferred, in social sciences, gender and/or human rights, epidemiology, medical anthropology, public health/HIV, evaluation or social research;
- Technical expertise in HIV/AIDS care and treatment; gender equality, and national health programming.

- A minimum of 10 years of experience in operations research/implementation science studies including publications in peer-reviewed journals.
- A strong record in conceptualization, design and implementation of operations research/implementation science projects.
- Experience working with diverse stakeholders groups: governments, civil society organizations (CSOs), PLWHIV, and the United Nations/ multilateral/bilateral institutions.
- Experience in participatory and action research approaches is an asset. Facilitation skills and ability to manage diversity of views in different cultural contexts highly preferred.
- Strong global knowledge and regional experience is preferred
- Strong ability to translate complex data and information into effective-written reports demonstrating high level analytical ability and communication skills.
- Detailed knowledge of the role of the UN and global HIV/AIDS policy frameworks is desirable.
- Proficiency in English required; with ability to work in French preferred.

# The Team Leader is required to submit two examples of reports recently completed where s/he contributed significantly as the lead writer.

#### The Review Team Member(s) should demonstrate skills in the following areas:

- A master's degree related to any of the social sciences, epidemiology, public health, medical anthropology or social research;
- At least five years of experience in HIV/AIDS care and treatment, gender, and national health programming.
- Extensive knowledge and experience in the application of quantitative and qualitative review methods;
- A minimum of 5 years of experience in conducting reviews and operations research/implementation science studies.
- Data analysis skills preferred (SPSS, STATA, Nud.ist, ACCESS, Excel)
- Strong analytical and writing skills.
- In-country or regional experience preferred
- Ability to work within a team.
- Proficiency in English required, with ability in French preferred.

### The review team should have gender balance and geographic representation.

#### **Annex A: Review Team Selection Criteria**

The selection of the Review Team will be based on the fulfillment of the specification established in the TOR. The submitted proposals will be assessed on three main categories: the quality of the technical proposal; the expertise and competencies of the review team, as demonstrated in CVs, gender balance and diversity of team; and the financial proposal. The categories are assigned different weighting, which will total 100%.

#### **Technical Proposal (35%)**

- **Statement of Interest**: including details of the experience of the company, references and prior relevant examples and how bidder's background fits the requisite competencies and skills.
- **Review approach and methodology**: The proposal presents a specific approach and a methodology for completing the global review of documentation and country-level studies clearly addressing the review questions in the TOR and specifying data collection and analysis procedures that are feasible and applicable in the timeframe and context of the review, and incorporates human rights and gender equality perspectives.
- **Timeline**: The timeframe and resources indicated in the financial proposal are realistic and useful for the needs of the review with milestones clearly indicated.

#### Team Composition (35%)

The team leader's and all team's experiences and qualifications meet the criteria indicated in the TOR. The team is gender balanced and cross-culturally diverse.

#### **Financial Proposal (30%)**

The budget proposed is sufficient for the data collection, analysis, presentation and further studies for the review in the timeframe indicated.