

DEVELOPING HARMONIZED INDICATORS FOR MONITORING PROGRESS ON GENDER EQUALITY DIMENSIONS OF THE HIV AND AIDS RESPONSES

TECHNICAL CONSULTATION
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CONVENED BY
UN WOMEN, UNAIDS, UNFPA, PEPFAR/OGAC AND MEASURE EVALUATION
IN PARTNERSHIP WITH
WHO, ICW, UNDP, and GFATM

EXECUTIVE SUMMARY:

- In late September 2011, UN Women, working in collaboration with a broad range of partners¹, convened a technical consultation. This consultation was designed to advance understanding and agreement on a set of harmonized indicators for countries to use to monitor progress on the gender equality dimensions of responses to HIV and AIDS.
- The meeting responded to the call for action on developing harmonized indicators in the *UNAIDS Agenda for Accelerated Action on women, girls, gender equality and HIV/AIDS*. The meeting built on previous discussions, including a meeting held over a year ago, and detailed debates that had occurred in the steering group, which has brought together a range of representatives (from UN agencies, bilateral donors, country stakeholders and community advocates) reflecting the broad range of over 50 participants gathered in New York for the face-to-face consultation.
- The focus of the meeting was a draft Compendium of proposed Indicators that are currently being used to track the gender equality dimensions of responses to HIV and AIDS. The task set for the 60 expert participants was to review this Compendium, categorize the indicators according to their relevance and ability to track key issues, and identify any areas where additional Indicators are needed and should be added to the Compendium from existing sources, or developed if they do not currently exist.
- It was emphasized throughout that this process was designed to complement and build on existing processes, eg UNAIDS MERG (Monitoring and Evaluation Reference Group), and not to duplicate in any way.
- Participants were asked to reach consensus on a small strategic set of harmonized gender equality and HIV indicators for use by national HIV programs, key partners/donors and other key stakeholders. They were also asked to begin to develop a strategy for dissemination that would support the use of these proposed indicators.
- Participants made excellent progress and succeeded in achieving the tasks set. The Working Group is currently considering further inputs from participants, and at the time of writing there are 88 Indicators – 44 of which were classified as Tier 1², and 18 of which were new additions to the Draft Compendium that was circulated ahead of the

¹ UNAIDS, UNFPA, PEPFAR/OGAC, MEASURE EVALUATION, WHO, ICW, UNDP, and GFATM

² For Tier 1: An indicator must meet the following five standards to be used in reporting systems:

1. The indicator is needed and useful.
2. The indicator has technical merit.
3. The indicator is fully-defined.
4. It is feasible to measure the indicator.
5. The indicator has been field-tested or used operationally.

meeting. Once the inputs have been made Measure Evaluation will revise the Compendium based on the discussions at the meeting.

- The prioritized list of 88 Indicators (see Annex A) contain:
 - 16 Service Related: Treatment, Counseling and Testing, Integration & Linkages (of which 7 are tier 1);
 - 27 Enabling Environment: MARPs (Most At Risk Populations), Policy, OVCs (Orphans and Vulnerable Children) and Male involvement (12 of which were Tier 1);
 - 20 Structural Determinants: Stigma and Discrimination, Gender Based Violence, Gender norms, women's autonomy & rights, Economic, literacy (11 are tier 1)
 - 10 Health Outcomes: Disease prevalence and impact, and Reproductive Health (9 of which are Tier 1);
 - 15 Individual Determinants: sexual behavior, knowledge about HIV/AIDS, Humanitarian emergencies and migration, trafficking in persons (5 are Tier 1)
- The working group, which continues to meet, is overseeing the feedback from participants who have been reviewing the decisions taken at the meeting. A number of participants have raised concerns that there are still no many priority indicators.
- The working group is also revising the Conceptual Framework that is being designed to place the Indicators in context and assists countries to utilize the Indicators.
- The final task to be resolved after the meeting is how to proceed in the areas where there was no consensus. These are generally contentious areas where there are diverse opinions on the relevance of the issue to the gender equality aspects of the HIV response, where data is weak, or it is hard to craft a sensitive measurement. The areas still being debated fall into the following categories:
 - Unmet need of sexual and reproductive health and rights (SRHR) services available on-site for HIV positive women
 - Maternal Mortality
 - Trafficking
 - "Couple" counseling and testing
 - Women's empowerment.
- The ambition is to resolve all outstanding issues by early 2012. There will then be a final round of input and review from meeting participants to ensure that the final product faithfully reflects the consultative process that has been core to this work.
- Over time it is hoped that the Tier 1 indicators will enable consistency across countries so that the gender aspects of the HIV response can be tracked effectively and improvements in the response to HIV and AIDS can easily be facilitated.
- Working with ICW, OGAC, MEASURE Evaluation, UNAIDS Co-sponsors and Secretariat and the Global Fund, UN Women will play a leading role in disseminating the final Compendium so that countries can benefit most from the product, and take better steps to monitor and enhance programming to address gender equality aspects of HIV programs at country level.

DETAILED REPORT OF THE MEETING

Purpose of the Technical Consultation:

This expert meeting had two broad objectives. To:

1. Review a broad set of proposed indicators for their relevance in measuring and monitoring gender equality dimensions of the HIV/AIDS epidemic in order to:
 - a. Recommend a strategic and small set of indicators from among those already in use in order to monitor the gender equality dimensions of the HIV epidemic through national and sub-national programs.
 - b. Provide an expanded list of indicators as a resource that specific projects, programs, research and interventions can choose from to measure, monitor and evaluate the gender equality dimensions of the HIV epidemic.
 - c. Put forward emerging areas of measurement for which indicators may need to be defined, refined and validated for future use,
2. Develop a strategy for dissemination and supporting the use of these proposed indicators.

Participants were informed that the following outputs were anticipated to emerge from the discussions:

1. Consensus on a strategic and small set of indicators for measuring and monitoring progress in addressing gender equality in the context of an AIDS response for use by countries.
2. A compendium of indicators. The compendium draws mainly on those indicators that are already in use, recommended to countries in guidelines and M&E frameworks (e.g. UNAIDS, WHO, PEPFAR, GF, MDGs), and can be collected through existing data collection and information systems (e.g. routine program monitoring, surveys). The **intended use of this compendium** is to strengthen countries and other stakeholders ability to know and understand their HIV epidemic and response from a gender equality perspective, to monitor trends towards eliminating gender-based inequities in HIV responses and design, and to monitor and evaluate programs that address specific types of gender equality interventions in the context of HIV. The compendium of indicators is **NOT intended** to: i) Provide normative guidance on all the indicators that every country should collect; ii) Replace existing internationally agreed to indicators (i.e. UNGASS and Universal Access) iii) Establish additional reporting mechanisms for countries. The compendium **IS intended** to: i) Provide a useful resource for countries and/or programs to better “know their epidemic/know their response” by using a gender lens; ii) Minimize measurement burden by drawing mainly on those indicators that are already in use, recommended to countries in guidelines and M&E frameworks (e.g. UNAIDS, WHO, MDGs), and can be collected through existing data collection and information systems (e.g. routine program monitoring, surveys). Where proposed indicators require specialized data collection approaches, this is specified³; iii) Highlight critical gaps in gender indicators in the context of an HIV response for consideration by national governments, research institutions, multilateral and bi-lateral agencies, civil society, and the international community at large.
3. Identification of actions to disseminate, promote and use the harmonized indicators.

DISCUSSIONS AT THE MEETING:

³ Existing indicators could be made more gender sensitive by ensuring both sex and age disaggregation in 5-year cohorts. However, altering agreed-to international indicators is beyond the scope of the meeting.

Most of the meeting was held in small groups where the expert participants took steps to consider carefully the range of indicators, their relationship to effective responses to HIV that would advance gender equality, and to identify any gaps in the exiting indicator set. The co-organizers had deliberately invited experts from a broad range of backgrounds, as well as diverse countries and all regions. This meant that academics, and evaluation experts were exploring the indicator set with women openly living with HIV, program managers, donors, UN and other technical support staff. See Annex C for list of participants.

Context

Background information was sent to participants ahead of the meeting (see Annex B) and the meeting opened with a review of why gender-sensitive measures are needed to monitor progress in HIV prevention, treatment, care and support, and the importance of identifying where to focus efforts. It was emphasized that indicators should track structural and proximal determinants as well as direct behavioral indicators, and acknowledged that structural determinants can impact both the causes and the consequences of HIV and gender (in)equality. Hence indicators that track the implementation of policy, legal issues and advocacy may be especially important. Qualitative data is extremely valuable, but it was accepted that this meeting would focus principally on quantitative data; recognizing the strategic importance of this type of monitoring on the basis that “what gets counted gets done”.

The group reflected on the many and varied roles that women may play and the broad range of groups of women who may have particular needs (eg women sex workers, women who use drugs, women carers). It was emphasized that the consultation was about gender rather than women, and so the gendered nature of the epidemic facing men (eg low rates of HIV testing, or access to care) or the needs of transgendered people should also be considered (although it was noted that there was very little to draw on in respect of transgender, and most indicators consider a simple male/female dichotomy). There was also significant concern about the age bands used for nearly all indicators falling within “15-49” range and thus exclude measurement of impacts on women and men over 50, and girls and boys under 14. While recognizing the issues of comparability with existing data sets, there were real concerns that substantial components of the epidemic are being missed, and this constrains efforts to develop programs reaching, eg older women vulnerable to HIV.

Country-Specific Considerations

“At the country-level, very few people understand why gender is important – we push for an agenda, but we don’t have one.”

The purpose of the proposed Compendium is to be a resource at country-level to assist countries to make sense of data through a gender lens. Before participants considered the indicators in detail, the meeting benefited from presentations from the Kenyan National AIDS Control Council, Rwanda’s Biomedical Center and reflections from Tajikistan on harmonizing gender-sensitive M&E. The profusion of data and indicator sets creates real challenges for country-based colleagues, who spoke of the difficulty in introducing new indicators, and the need to understand and articulate the importance of new indicators if M&E people are to be able to integrate them into their data collection systems. If there are too many indicators then it can be extremely difficult to use them.

The conceptual framework

A conceptual framework was offered to the group as an approach to organizing the range of issues and indicators touching on the gender-equality dimensions of AIDS responses. While the participants appreciated some aspects of the framework, such as the distinction drawn between structural and proximate determinants (although there were concerns about what was placed where), they also felt quite strongly that the Framework did not help to articulate the complexities of the issues and at times muddled various areas. For example the issues facing MARPs (Most At Risk Populations) are cross-cutting and relate to most of the other issues, but certainly do not occupy the same space as "Policy" or "OVCs", yet all three were placed in the category of "Enabling Environment". There was also significant concern about the use of a category of Long-term outcomes. This was not felt to be appropriate (and there were many elements missing, with some determinants also being outcomes). The list of key populations was also contentious and needed unpacking, and some preferred different terminology, eg "Populations in situations of vulnerability". It was agreed that clear descriptions of terms used would be included.

It was acknowledged that this Framework was offered to show clear links between gender equality and HIV, as well as to be able to place sets of indicators. However, there are many areas that are thematic and cross categories and so it was proposed that there should be cross-referencing with relevant indicators "tagged" to recognize that they spanned more than one category. It was also suggested that the Framework may be better named as an "Organizing Framework" rather than conceptual. This was agreed. One concern was a lack of clarity about the human rights context for the framework. Many participants asked for this structure to be re-considered and for an ecological framework to be explored as a potentially better organizing framework.

A working group was convened and endeavored to come up with a better organizing structure that told the story more clearly, but after lengthy discussions it was agreed to defer this and for a proposal to be made by the Working Group after the meeting. This report is organized according to the Framework provided, but it is anticipated that the final Compendium will be structured differently.

Areas of Non-consensus

Overall the meeting participants were able to find consensus on most issues and this was a harmonious gathering. There were some significant areas of non-consensus, requiring important extra work and debate, but these fell into only a small number of topics:

- *Unmet need of sexual and reproductive health and rights (SRHR) services available on-site for HIV positive women*
- *Maternal Mortality*
- *Trafficking*
- *"Couple" counseling and testing*
- *Women's empowerment.*

The reasons for a lack of consensus varied between technical considerations (eg maternal mortality) and broader debates about rationale and the link between the issue and HIV vulnerability (eg trafficking). The Working Group agreed to consider these questions in more depth so as to develop next steps and consider how these areas could be addressed in the compendium.

In all cases, the issues that were debated were complex. In respect of *Unmet need of sexual and reproductive health and rights (SRHR) services available on-site for HIV positive women* there was no questions that this is a key issue, and that women living with HIV require access to quality SRHR services. The lack of consensus centered on identifying an appropriately specific and sensitive measurement that could track process. There were concerns that a focus solely

on family planning would miss the diversity of needs that women have, especially women living with HIV.

In respect of *Maternal Mortality*, there was an appreciation that this is a key issue – garnering substantial global attention - but a concern that the linkages with HIV vary substantially between countries and regions, and that there are technical constraints that limit effective measurement of maternal mortality in most settings. While several participants emphasized the importance of finding ways to track the links between maternal mortality and HIV, others felt that it was too challenging at a technical level and should be dropped.

Perhaps the most hotly debated issue was that of *Trafficking*. There was limited discussion of the technical considerations of monitoring the issue, with rather quite polarized debates about the degree to which HIV and trafficking are linked. Some participants felt passionately that there was an important HIV vulnerability associated with trafficking, whereas others queried the whole concept of “trafficking” and raised questions about the relationships between HIV and sex work and notions of “trafficking”.

“*Couple*” *counseling and testing* was also a category where consensus could not be reached. This issue fell somewhere between the extremes. Some participants questioned the value of couple counseling in delivering desired outcomes, whereas others raised concerns about the best methodologies to monitor this aspect of service delivery. The question of *women’s empowerment* centered most on methodologies: how can empowerment be tracked and evaluated? The means of measurement are complex and contested.

The Indicators

In small groups the expert participants considered a range of indicators which are currently in use, reviewing their pertinence and ability to track the gender (in)equality dimensions of local AIDS responses. Once they had evaluated existing indicators, and identified other indicators in use that were not proposed in the draft compendium, participants then categorized them according to Tiers (see footnote 2); in addition they identified areas where indicators are required, but do not currently exist. In respect of the “new” indicators, it was acknowledged that this meeting, and the resulting Compendium, cannot design new indicators, or set a process to do so, but that it is appropriate and helpful to identify the gaps in the hope that future processes, led by participants and others, will be able to take work forward to address these issues. There was a general feeling that the Compendium should be a dynamic resource that can be updated as new indicators are field tested.

What follows is a summary of the key issues emerging in each of the content areas. The detail of the agreed indicators can be found in Annex C, as well as ultimately in the Compendium.

Service Related:

Treatment

The agreed treatment indicators are quite standard and create the appropriate baseline for data gathering that can then be boosted through gender disaggregation (which could reveal unexpected findings, eg men may have inadequate access to treatment rather than women (because of women’s access to health services during pregnancy and child rearing). In addition it was felt that barriers to accessing treatment should be tracked, for example considerations such as travel, time and distance. There were concerns about finding appropriate and usable indicators to track loss to follow-up to ensure that once women come for an HIV-test, they continue to receive care and support.

There were some concerns about where some of the indicators belong, and a need to ensure that TB, Hepatitis B and C and maternal mortality were included and that the references were consistent. The indicator on the number of health facilities providing PEP services on site was

omitted as it was considered that this was covered under GBV, but this caused some concern as PEP may be required for other reasons.

Counseling and Testing

In general this section was rather straightforward and there was little debate. Service issues, in particular counseling for sexual health, sexually transmitted infections (STIs) and sero-discordance, were identified as key issues that were insufficiently addressed. The issue of partner testing and counseling was highlighted as especially important, but there were concerns that the current indicator available to measure partner counseling is too restrictive (since it is focused on partners being counseled and tested on-site).

Integration & Linkages

The most vibrant discussion in this area focused on how to track access to a broad range of sexual and reproductive health and rights services, especially for women living with HIV. The indicator tracking the unmet need for family planning was highlighted as a good indicator, but most participants felt that it was insufficient to track the range of concerns that they have. There was also a clear request to replace the term “family planning” with SRHR, in recognition that the needs faced by women living with HIV (& at risk) are far broader than family planning. This led to a substantial debate about whether or not to remove indicators solely about family planning – without them it would be hard to track contraceptive need, but it could still lead to a reductionist approach to the needs of women.

A number of detailed concerns were also explored, including picking up the issues flagged under Treatment about how Hepatitis (B or C) is being tracked, and how to ensure that HIV & TB is monitored. Non-communicable diseases were also highlighted as a gap. There were also suggestions that referrals should include linkages to mental health services and to food security.

Enabling Environment:

MARPs

A key consideration here is population size estimates; it was agreed that countries should endeavor to collect data on the numbers of female drug users, sex workers etc. It was noted that the UNAIDS Inter-agency working group has established M&E operational guidelines for HIV prevention for sex workers, men who have sex with men and transgender people. There were some questions about what added value there would be from sex disaggregation here – one example given is that women drug users are often have limited access to services so disaggregation of data on syringe distribution per drug user per year might speak to these questions. The needs of women prisoners was also raised, and this highlighted the need to clarify the definition of “MARPs” and which populations are included. It was also noted that there was no focus on transgendered people. It was proposed that recommendation 4 (in particular) be reworded so that it does not exclude transgender people. A number of these issues echoed points raised in the discussions about the “Conceptual Framework”.

Policy

Participation of women living with HIV in decision-making roles, in organizations and government is important, as is an indicator that can track gender expertise. Gender budgeting is also important, ie the percentage of countries with a multi-sectoral strategy which includes women and has a specific HIV women’s budget. However, there were concerns that this indicator could be too imprecise, as it may not express whether the budget is sufficient, or whether it was spent (was action actually taken). It was noted that there is an existing indicator in the UBRAF (Unified Budget, Results and Accountability Framework) that addresses Gender Plans that incorporate HIV. It was proposed that this indicator is included.

An improved indicator is needed to measure the existence of policies and guidelines to address the intersection of gender-based violence and HIV in strategic sectors, including health and justice. Also, while it is important to track the proportion of law enforcement units following a nationally established protocol for violence against women complaints, the indicator does not capture psychosocial services that should be available to women.

In respect of policy “rights literacy” is important as is the role of civil society, including women’s groups, as a “watch-dog” for ensuring policies are implemented, and to ensure accountability – to go beyond representation in decision-making, and take this to the ground level. Advocacy related indicators can track the enabling environment for advocacy, as well as implementation, and monitoring of policy implementation.

OVCs (Orphans and Vulnerable Children)

There was concern about using indicators focused explicitly on OVCs. However, it was felt that dropping the indicator (because it is not sufficiently gender-sensitive) would limit ability to plan equitable provision of services, and put in place the policies to know what kinds of services are needed. It is, of course, imperative that OVC data is sex disaggregated. It was felt that the indicators should be aligned with the new UNGASS indicators, and that the additional gender dimensions drawn out in discussion in reference sheets. There was some discussion that OVCs indicators might fit best in another category, such as care and support.

Male involvement

A number of variables were discussed that could speak to enhancing male involvement. These include the delivery of comprehensive sex and reproductive health education, that includes human rights and gender equality; tracking men’s support of gender equality, for example the proportion of men who say that they would take action to stop gender-based violence. The GEM scale was suggested as one option, although there were some reservations. It was suggested that this needs a number of indicators, to look at men’s understanding, and also their involvement. There is a correlation between being involved and being informed. It was agreed that it was important – but difficult – to measure men’s action to bring about gender equality, and to identify when men are “part of the solution” rather than the problem. There was a recommendation that the indicators identified in the male involvement section should be integrated in the gender norms or policy sections, as appropriate, and then be cross-referenced.

Structural Determinants:

Stigma and Discrimination

The indicators on stigma & discrimination were relatively non-contentious, as in the main it did not seem that there were significant gender dimensions to the issue. There was a discussions about the need to include a measure of self-stigmatization, and there was some consideration of modifying one of the indicators. Overall there were some concerns that the questions around discrimination and stigma need to be more relevant and current.

Gender Based Violence (GBV)

The Indicators selected by participants were designed to ensure that it would be possible to track reports of violence that could be related to HIV. It was recognized that this is a key area, and extremely complex, with related indicators being identified in a range of sections. It was hoped that the GBV indicators could be “pulled out” and highlighted in the compendium. The group decided that the term GBV should be used rather than “Violence Against Women and Girls” (VAW/G). It was also acknowledged that there should be further consultation to address groups that were not represented, including transgendered people.

Participants welcomed the fact that a new indicator on intimate partner violence (IPV) has at last been included in UNAIDS core indicator set that monitors Global AIDS progress. This indicator -

Proportion of ever-married or partnered women aged 15-49 who experienced physical or sexual violence from a male intimate partner in the past 12 months -measures progress in reducing prevalence of intimate partner violence against women - as an outcome itself, as well as a proxy for gender inequality. Data collection on violence against women requires special methodologies to ensure that information is gathered in an ethical manner that does not pose a risk to study subjects, and in a way that maximizes data validity and reliability. Population based surveys that are already being used within countries, such as WHO Multi-country surveys, DHS/AIS, International Violence Against Women Surveys (IVAWS) will be used to collect data against this IPV indicator every 3-5 years.

The group was focused on using this new indicator, recognising that it was well developed and important to now put into practice. There was a request for a parallel indicator focusing on “ever” IPV (rather than just “recent” IPV). The most significant “missing” indicator that needs to be developed is to measure violence against women living with HIV. In addition, participants highlighted the importance of measuring:

- Adoption of clinical management of GBV within HIV services
- Providers trained and have competency skills
- HIV sero-conversion after PEP (although it is unclear how this could be tracked)
- Population-based measurement of sexual violence among girls.
- Violence in MARPs

The issue of PEP (Post Exposure Prophylaxis) was identified as particularly tricky: would an indicator be able to look into facility level availability? Would this only relate to PEP for GBV? Reliable tracking of the impact of PEP requires pre- and post-PEP HIV testing which may not be practically and ethically viable in many cases.

In addition further work was requested to look into the questions of psycho-social support and violence prevention – the need to track girls and boys observing IPV was highlighted. There was also important discussion about how easy it is to report violence given that self-report is complicated, and women may not recognize behavior as violent *per se*. This could be especially challenging amongst married women.

Gender norms, women’s autonomy and rights

The issue of male and female gender norms led to intriguing debates, considering how to track men’s sense of entitlement to sexual activity (eg with a sex worker, to types of sexual activity) and types of partnership. This discussion also touched on concerns about male norms around not seeking care, as well as female care giving, and the equitable division of the burden of care and valuing care giving (unpaid care). It was highlighted that there is data to support issues concerning male gender norms, especially regarding male disclosure of status. Norms around care and support are complex and it is hard to envisage indicators that will recognize the different types of caregivers. More work on developing indicators that will track the “care economy” was strongly recommended.

There were discussions about female norms around childbearing, and reproductive role as well as sexual decision-making (including norms for older women). One group tried to develop new indicators that would address women’s autonomy in the bedroom, but this was tricky. Some looked at power relations, trying to find an indicator that determined whether or not women were in control of their sexual relationships (which would be a marker), but none was identified. It was proposed to add an indicator that would track (and disaggregate by sex & age) the proportion of women and men who say that wife beating is acceptable if she refuses to have sexual intercourse with him.

Some additional areas were also highlighted, including steps to capture information on: engagement of HIV+ men in policy/programs; sexual decision-making; awareness and access to legal protection for women and girls impacted by HIV.

Economic/literacy

There were few indicators available in this area, despite the fact that there is clear concern about the relationship between poverty and HIV. There was a desire for a general indicator, but none was apparent. It was agreed that data on the poverty status of women living with HIV should be compared to women who are HIV negative. It was hoped that an indicator could be found that would look at economic programs or schemes targeted towards key populations. In respect of literacy there were interesting discussions about treatment literacy and the need to track the proportion of people living with HIV who have adequate treatment literacy. This area was especially important in respect of age (& the failure of most indicators to track issues facing older women). Women over 49 years old are often caregivers, as well as living with HIV themselves. The issues surrounding property ownership are especially important given women's role in caring for their family (eg often older women sell their own possessions). It was also emphasized that the treatment literacy of caregivers, as well as women living with HIV is important since caregivers play a key role with treatment enrollment and adherence.

The intent with a literacy indicator is to track broader issues as literacy comparison is often a good proxy indicator for access to education. The group looking at this felt that tracking completion of 10 years of education was likely to be a more meaningful indicator, than one that might record very basic levels of literacy.

In respect of the indicators tracking wage employment, the core issue is control of money, and the problem is that these indicators do not reflect whether or not women keep the money they earn. While there were similar concerns with land ownership this is less contested. It was proposed to also look at the DHS indicators about decision-making, which may be useful.

Health Outcomes:

Disease prevalence and impact

In this section there was some overlap with the treatment section and there was discussions about where various indicators, eg on TB and cervical cancer, would be best placed. There were also concerns to reflect the gender and HIV links with regard to syphilis and fertility. It was suggested that a category on seeking care or service utilization could be useful (as this is likely to impact outcomes). The issues of length of time on treatment and survival indicators was raised, as was the need for an indicator tracking quality of life of women on treatment (what are the long term effects of treatment?) Simply counting the numbers of women on treatment misses many factors, including the quality of services. Mortality modeling and life expectancy should also disaggregate by men and women.

Health related outcomes from PMTCT programs was also highlighted as a key issue. There is currently limited, if any, data on survival and follow up of women who have been on PMTCT programs, and reporting is patchy. It was acknowledged that this is complicated. Current indicators would measure if women are on treatment, but not reflect whether they receive care. A distinction also needs to be drawn between women who need treatment for their own health when they get pregnant and need treatment and those who don't need treatment for their own health. There is currently no indicator to track women's survival 12 months post-PMTCT. This was identified as an important quality issue where countries must be encouraged to report.

Participants also wanted to ensure that steps are taken to track outcomes for children, and to monitor HIV testing for children who have been exposed to HIV. It was proposed that the

Compendium should link to other references, such as the guide produced by WHO and UNICEF M&E of PMTCT programs.

Reproductive Health

This is a key area, but complex to monitor. This section endeavored to elucidate the areas that needed attention, and did not fall under health outcomes. It could be helpful to track access to reproductive health services, including STI prevention and treatment, disaggregated by sex and HIV status. This could also be the space to track the existence of policies or strategies to ensure access to HIV prevention, treatment, care and support for women outside the context of pregnancy and childbirth, as well as access to, and use of, female condoms. The issues surrounding cervical cancer also fit here – and are complicated given the higher rates of cervical dysplasia (& cancer) among women living with HIV.

The most contentious issue in this area was the question of monitoring maternal mortality. Participants were not able to develop an indicator that would measure complications at childbirth related to HIV-status, but at the same wanted to capture the relationship between maternal mortality-ratios and HIV. In general it is hard to measure how women die in childbirth, which makes defining the HIV-related dimension even more challenging. Several participants felt that the maternal mortality ratio is not a good maternal health indicator let alone an HIV indicator.

Individual Determinants:

Sexual behavior

Sexual behavior indicators are well developed and there was minimal debate on these items. It was proposed that more work should be developed on the use of microbicides and female, as well as developing a deeper understanding of why women are not using condoms. The issues of female autonomy (eg violence & condom use) forced sex and transactional sex were also raised here, as was the question of marital rape.

Knowledge about HIV and AIDS

The overall consideration is that while knowledge may not be a gendered issue, access to knowledge is. It would help to have data on knowledge on a range of other issues, including the existence of, and access to, female condoms; legal age for marriage; existing laws on marital rape.

In the context of knowledge indicators, the question of age was raised again, In particular it was noted that capturing data on knowledge of the age group 10 – 14, not just 15 – 24, would be important. It was reported that UNESCO is about to release a framework for HIV M&E and they have the same indicator knowledge indicator, but this starts at age 10.

A number of new items were proposed, which would give more structural information. These include whether the Ministry of Education has a dedicated committee to coordinate the HIV response, whether they have received training on gender equality and sensitivity; is there a gender-sensitive HIV awareness program for employees; the existence of support materials, orientation and training for teachers, and for parents in a range of areas: SRHR, Sexuality Education, gender equality & gender empowerment and stigma. It was hoped that the UNESCO resource would cover this.

Humanitarian emergencies and migration

The major issue here focuses on sexual exploitation, abuse and rape that may occur in these contexts. Measures include the number of people who feel confident about reporting sexual abuse/exploitation, and are confident that they would be treated fairly. Protocols have been established for the comprehensive response to survivors within the emergency context and

these should be tracked. It was proposed that a sex disaggregated indicator on HIV prevention should be highlighted, and there should also be an indicator (existing in UNHCR HIS) on the distribution rate of male and female condoms within refugee camps and IDP settings. There was limited knowledge about what is currently underway to track HIV and gender dimensions in emergency settings, and a suggestion to cross-reference the data (Erin Kenny and Beth Van were identified as important resource people for this).

An important concern was raised that tracking sustained and reliable access to ARVs for displaced people living with HIV may not be adequately addressed. TB and non-communicable disease prevalence also need attention in this context. It was emphasized that indicators speaking to migration should be in a separate area. There is a body of knowledge and experience in this area, and the potential to make explicit links to patterns that lead to the gender dynamics of HIV risk.

Trafficking in persons

The discussion on trafficking was heated and there was too much disagreement that meant it was impossible to even agree whether this was the right setting to address trafficking, and several voices stating that it would not be appropriate to develop indicators on trafficking for the compendium. The link between HIV and trafficking was contested with strongly held views on both sides.

Additional Considerations for the Compendium

Participants were pleased with the work undertaken and keen to ensure that the Compendium could be used most effectively, noting that in at national level, and in different sectors, people may use this for a range of purposes. It will be important to have clear “instructions for use” as well as ensuring that information is clear, eg with precise definitions for the various terminologies used.

There will need to be a justification for including each indicator in the guide, explaining how it relates to gender and HIV, for each reference sheet. This will include use and purpose. It might assist to have a sub-heading “interpretation and analysis” to help the user understand what the sex disaggregation means, or questions to ask from the analysis so as to interpret the data well.

New categories were proposed for the compendium these included: care and support (to track provision at the household and community level), prevention and advocacy. Tags for some of the indicators that fit into multiple categories would be helpful, as well as an Annex showing the range of categories to make it more user-friendly. It was emphasized that the Compendium should be a dynamic resource that can be updated as indicators are field tested and become available for wider use.

Next Steps

“This is another call to action”

One key issue that requires attention is the question of age bands. It was emphasized that approaches to indicators need to be “fit for a 2010 epidemic”, which means acknowledging that women aged over 50 are living with HIV, sexually active and also central to the care economy. The needs of girls under the age of 15 was also stressed repeatedly during the consultation. On a separate note, the need to address transgender issues came up repeatedly, and the Working Group stated that they would take steps to address this and consult with relevant groups.

The other critical area that was not resolved at the Consultation was the need for qualitative analysis. Participants asked the working group to determine how this will be taken forward.

These are important areas for future work. It was noted that the Compendium would flag these issues but that the Working Group was not constituted to make decisions about how this would be advanced. Of course individual members of the working group do have the power to advance some of these agendas and agreed to explore this further within their own agencies.

Areas for Further Research

Specific areas were highlighted for attention before the Compendium is completed. These are highlighted in Annex A and include the following key areas:

- Care and Support
- Empowerment of Women – specific to decision making in national processes
- Transactional Sex – may have indicators here
- Quality of Care Indicators – may have indicators here
- Education – check UNESCO indicators
- Treatment literacy
- Female Condoms and use
- Quality of Life Indicators

Research Agenda:

In the longer-term there is a need to explore the development, field testing and use of indicators in the following areas, where there are currently key gaps. Developing indicators in these areas is important to ensure a comprehensive and quality approach to gender equality and HIV. Areas are highlighted in Annex A and include:

- Microbicides and use
- Integration for non-communicable diseases and HIV
- Prison populations and gender dynamics
- Understanding violence against women living with HIV
- Meaningful engagement of women living with HIV in policy
- Female condoms
- Migration

Dissemination strategies:

“My vision of measuring gender has been changed; I will apply this to my work”

Participants identified a range of ways in which they would support distribution and use of the Compendium once finalized. Civil society representatives present stated that they would link the Compendium with existing initiatives, and use the Indicators in M&E activities for their own programs. They would share the Compendium through existing networks and ask governments and donors to use it and to support indicator development and testing. They would also engage with the UN in processes to sensitive governments to the Compendium and to encourage them to use it.

The UN representatives will disseminate the Compendium through internal processes, and this will be a key strategy in support of countries. They will also introduce it at the UN and partners’ meeting on the Agenda for Women and Girls, in the context of knowing your epidemic and building a response. UN colleagues pledged to support an initial set of countries to use the Compendium, including through the development of case studies, and supporting South-South collaboration. It was proposed that the UN and donors should also organize together to come up with a strong advocacy strategy with countries’ policy makers for them to endorse this work and enhance their commitment to the work.

Researchers present agreed to gather the additional data required, and conduct Operational Research using the indicators. They would also analyze existing indicators and look at the new areas that were highlighted.

The donor representatives also pledged to disseminate the Compendium through internal processes, making sure this reached a broad audience beyond HIV, as well as disseminating to their partners, including colleagues in country and other donors. Donors also pledged to provide a feedback loop on how the Compendium is being used in the field – collection of lessons learned. They proposed to link to the 10 goals of the UNAIDS UBRAF inclusion, as appropriate, and to share the Compendium with other co-sponsors as needed.

Representatives from the Country level said that even before the Compendium they would identify entry points to include the indicators. They would engage in advocacy efforts at the country level to include these indicators. They noted that they would need support for capacity building, technical assistance on how to use the indicators, and support to work well with civil society, as well as to inform agencies that conduct HIV surveillance in concentrated epidemics.

Conclusions:

“I think this has been an unusually productive meeting”

Participants were warmly appreciative of the Expert meeting and found it to be very productive. Most felt that the Compendium would be incredibly valuable as an advocacy tool, as well as for program management and evaluation. Several participants could already identify real applications for their personal work. They felt that many people would be interested in this, and it would not just be applied to HIV programs, but to people in other areas who would be very interested as well. They felt that the issue of communicating with colleagues and partners would be key, and they looked to UNAIDS and UN Women, in particular, to work with country teams to make sure this work was integrated in National Strategic Plans.

Annex A: Final indicators List – Tiers and Areas for Further Development

Annex B: Background to the Technical Consultation

Annex C: List of participants.

Annex B:

Background to the Technical Consultation⁴

Gender equality is undoubtedly a key driver of HIV and AIDS epidemics. Gender norms, roles and relations make women and girls, as well as men and boys, vulnerable to HIV in different ways. In most societies unequal power relations and inequities in access to and control over resources between women and men, and the lower status of women compared to men puts women and girls especially at risk and vulnerable to HIV. It is also recognized that harmful gender norms and practices related to masculinity also play a key role in men's and boys' risk and vulnerability to HIV.

Therefore, HIV and AIDS responses need to and must address and track progress towards gender equality by addressing the needs of women and girls as well as harmful gender norms and practices affecting both women and men. Increasingly key stakeholders and actors in the AIDS response are calling for the effective tracking of progress in addressing gender equality in the context of HIV. Gender-sensitive indicators therefore, can be powerful tools to promote the tracking of changes over time or in reference to a group, for example men or women who are HIV negative. Gender-sensitive indicators can help measure how gender inequalities affect HIV and AIDS and hence inform how programs, policies and services should be best designed to address the specific needs of people most affected. And they can help monitor the progress made by programs in reducing these inequalities. Evidence is showing that interventions, particularly those that seek to reduce the impact of the HIV epidemics on girls and women require the knowledge and courage to address gender inequality.

One critical challenge of assessing the effectiveness of programming to respond to gender inequalities in responses to AIDS is the lack of appropriate and agreed-upon indicators. While many gender indicators have been identified in AIDS programming, they have not become part of the global standards for monitoring women's rights or empowerment within the framework of the UNGASS (UN General Assembly Special Session on AIDS) indicators and even fewer link to national strategic frameworks on AIDS at country-level. Common indicators to assess the gender dimensions of HIV must be promoted, and mechanisms set in place to monitor the impacts of policies and programs that are responsive to gender equality priorities. There is a gap in information about the impact of interventions that address gender equality and gender transformative efforts within the HIV response primarily due to the fact that existing indicators within the UNGASS core indicators tend to be concentrated around "biomedical" approaches such as condom use, prevention of mother-to-child transmission, access to ARVs (Antiretrovirals), and knowledge and information on prevention. This makes tracking of efforts to promote women's rights and empowerment through AIDS programming difficult. Most efforts to-date have focused on individual behavior change without consideration of the structural conditions (i.e. social, legal, political, economic inequalities) that contribute to the spread of the epidemic. Thus a more encompassing approach to measure the impact of interventions that address these factors must be undertaken and data needs to be gathered to do so.

Gender-sensitive HIV indicators rely on sex-disaggregated data in prevalence, incidence, sexual behaviors, knowledge, access to services etc. In addition, indicators are also required to capture gendered power relations between women and men as a key structural determinant of HIV. Furthermore monitoring gender-based inequities in HIV require data to be further disaggregated by age, urban/rural, ethnicity, disability, marital status and other factors that are important within a particular context. While quantitative indicators are important, several

⁴ This background paper was provided to all participants in advance of the meeting Expert Meeting on Developing Harmonized Indicators for Measuring Progress on the Gender Equality Dimensions of HIV and AIDS 21-23 September, 2011 – New York

aspects of measuring and monitoring gender inequalities require qualitative indicators as well as other types of qualitative data in order to better understand why certain patterns in behavior or outcomes occur and how such situations can be changed. The resources available for data collection and the gender issues that are most relevant to the program and project determine the selection of indicators.