

Consensus building for developing gender-sensitive leading health indicators¹

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Summary

Objectives: This article seeks to describe the process of reaching consensus for a gender-sensitive set of leading health indicators between and within multi-level stakeholders from various cultural, social and economic conditions.

In 2000 the WHO Centre for Health Development (WKC) embarked on a multilevel participatory process aiming at the formulation of a well-accepted set of gender-sensitive leading health indicators – and considerable interest in their use. Different stakeholders have different needs and demands for information. Failure to reach consensus between the relevant actors led to the development and use of indicators by different groups, creating situation of confusion for end users of data.

Methods: The consensus process took almost two years starting from 2003 and WKC played a facilitating role in this process. The consultation process was done through different mechanisms ranging from international meetings, online voting and expert group meeting.

Results: The core set of indicators was brought down to 34 leading health indicators and was pilot tested in two sites. Preliminary results of the pilot testing showed that the set was considered as valuable tool for policy and decision-making at various levels.

Conclusion: The consensus over the gender-sensitive core set of leading health indicators was a relatively long and extensive process and required some kind of creativity to identify appropriate platforms for consultation. But the key point is that perspectives of multiple stakeholders were included as much as possible.

The process of selecting health indicators to inform policies and programmes must be participatory in order to ensure that views of multiple stakeholders are integrated (Rifkin & Pridmore 2001). Current sets of health indicators used to inform policy and programmes have failed to do so. The WHO Centre for Health Development (WKC) has set-up mechanisms for reaching a consensus for a gender-sensitive core set of leading health indicators, which has enabled multi-level stakeholder participation in the process.

Since 2000, WKC held a series of international meetings to discuss issues related to gender and women's health (WKC 2000; WKC 2001; WKC2002b). Participants of these meetings were decision-makers, representatives from non-governmental organizations and academia. Concerns were raised about processes of data collection, analysis and use especially those to inform decision and policy-making processes (WKC 2000). Civil societies working with marginalized women groups raised concerns about the lack of evidence regarding women's health (WHO Report on Third International Meeting on Women and Health (WKC 2000)). Participants agreed on a plan of action for women and health (Kobe Plan of Action for Women and Health (WKC 2002a)) and identified the evaluation of indicators as a priority research area for the WKC and set-up a task force to implement the plan.

Subsequently, the La Trobe Consortium was commissioned to conduct a review of existing indicator (WKC 2003) on existing indicator sets including sets from the World Health Organization Office for the Americas. The research group conducted an audit of 1,095 indicators using the seven Beck's criteria for selecting indicators (Beck 1999; Beck 1997) (see annex 1):

- participation,
- relevance,
- disaggregation,
- comprehensibility,

¹ See annex 4

- clear and explicit,
- small in number; and
- specific.

Those involved in data production processes need to have sufficient knowledge of the context under scrutiny (Williamson et al. 2001). Unfortunately, current health information systems still place heavy emphasis on measuring and analysing policy and programme achievements. This is done by people who are too often disconnected from the social context such as government officials which leads to a situation of bias. The report produced by the La Trobe Consortium addresses the failure of current governments to involve key stakeholders. As a result of that failure, current indicator sets lack gender-sensitivity and equity dimensions. Different groups of stakeholders have different interests and needs for information, which explains the proliferation of numerous sets of indicators.

When information about an issue is produced by various stakeholders, it can be confusing, as sources tend to tell stories from their own perspectives. If data is produced to inform policy and stimulate action for positive change, it is critical that multiple stakeholders contribute to the data production process and this monitoring takes place as a social process at local, national, and global levels. In addition, participation of multiple stakeholders and sectors would ensure that the indicators selected are accepted and supported by the end-users. In the La Trobe Consortium report, the research group made several recommendations to improve the current health information systems and suggested having a core set of leading² health indicators integrating gender perspectives and social processes as part of the monitoring process. Such an indicator set would be a useful tool for policy-making and effective and efficient health monitoring.

This article intends to describe the process in reaching consensus for a gender-sensitive core set of leading health indicators. The first part of the article provides a brief description of the methodology used for consensus building. The second

part refers to the validation of the indicators followed, thirdly, by a discussion on the importance to establish a monitoring system as a social process and social accountability, and, fourthly, is concluded by a short assessment and outlook.

Methods

Stakeholders comprised individuals or groups dealing with gender and women's health from different sectors such as officials, academia, and civil societies. The consensus process took almost two years starting from 2003. WKC played a facilitating role in this process. It created different formats of consultation mechanisms to ensure broad participation of multiple stakeholders in the process. These platforms ranged from international, online consultation to expert group meetings. The set of indicators was finalized in four stages: Tanzania meeting, online consultation, expert group meeting and the consultative meeting.

Tanzania meeting

In October 2003, WKC organized its Fourth international meeting on women and health (here referred to as the Tanzania meeting). The aim was to report the achievements of the Kobe Plan of Action. The outcomes of the La Trobe Consortium report were discussed at a workshop during the meeting. Participants of the workshop included a mix of academics, policy and programme developers and deliverers, and representatives of civil societies at national and sub-national levels.

The first consensus was reached on the issues related to terminology. It was pointed out that some conceptual apparatus amongst the indicators needed to be clarified so that different groups of interest could reach a mutual understanding of the terms. For example, "sex-disaggregated" and "gender-disaggregated" should not be used interchangeably as this would be confusing and result in the collection of incorrect information.

Representatives of civil societies reiterated that data collection and analysis is costly. Another problem posed the sheer number of indicators which are not necessarily relevant in a resource-limited organization. These representatives suggested building on existing well-established international mechanisms such as the Millennium Development Goals (MDGs) and using national reports. However, the NGOs expressed concerns about data collection, use and compilation in national reports which inform policy and programme processes. When data is compiled and published within a national or international report, it loses local specificity. Consequently, initiatives proposed nationally are not necessarily appropriate locally and vice versa.

² The concept of "leading health indicators" builds on the approach developed by Healthy People 2010 (Chrvala & Bulger 1999) "Leading" health indicators, unlike traditional indicators, have a predictive capability. Predictive indicators tend to be more 'upstream' – such as risk factors, rather than deaths and diseases. They ideally are also contributory factors for a range of health outcomes, so that the return on investment on preventive action is greater. Infant mortality would be a monitoring indicator, whereas tobacco use would be predictive. Therefore, leading health indicators are applicable to a range of socioeconomic settings and health conditions and can capture gender-related changes in society over time. Leading health indicators are highly applicable to a range of health outcomes, so that the return on investment in preventive action is greater.

Participants considered that there was great value in having a gender-sensitive core set of leading health indicators and made several recommendations to guide the work. They pointed out that the set of leading health indicators needs to be applicable nationally and locally to enable community-targeted actions. In addition, participants specified that indicators must be developed and measured through participatory approaches including women.

Aware of the lack of skills in data collection and analysis of a variety of stakeholders, participants of the Tanzania meeting addressed the need to include a capacity-building component to the project to ensure the involvement of relevant stakeholders. Capacity building would enable individuals or groups of individuals to become more conscious of their own situation and organize collectively over an issue.

A list of indicators was presented to the participants, who were then asked to tick indicators they considered should be included in the core set of indicators. Recommendations from the Tanzania meeting and the list of topic indicators were again revisited and adapted at a subsequent online discussions and meetings described below.

Online consultation with task force members

Members of the online consultation included members of the Kobe task force, participants of the Tanzania meeting and additional experts working on indicators, gender, women's health and equity issues. These additional experts were contacted by WKC to contribute to the project via emails. A chat room was created for that purpose and participants posted comments and feedback on the list of indicators from the Tanzania meeting.

The expert group meeting

The subsequent expert group meeting was a three-day meeting held in November 2003. Participants comprised experts on gender and women's health, statisticians, representatives of national institutes, representatives of international organizations including the United Nations Children's Fund (UNICEF), United Nations Development Fund for Women (UNIFEM), the Organization for Economic Cooperation and development (OECD) and other offices of WHO.

The experts built on the recommendations from the Tanzania meeting and work from the online consultation. The experts considered that a core set of leading health indicators would be a powerful instrument for decision-makers and operational staff and would contribute to:

- strengthening capacity at all levels for monitoring gender equity in health
- improving effectiveness and efficiency of national health monitoring systems

- improving the gender sensitivity of current data
- identifying leading indicators for monitoring purposes and for early warning systems
- developing new indicators to address gaps and other inadequacies of current systems.

The experts used the Health Information Framework (HIF) developed by the OECD and the International Standards Organization (ISO), which had been further adapted by the La Trobe Consortium. The HIF was modified into three areas:

Tier 1: Health status (overall health of a population)

Tier 2: Determinants of health (individual, household, community and national)

Tier 3: Health and welfare systems performance (delivery and quality of services).

Experts also proposed the following set of criteria to be used for selecting the core set of leading health indicators, i. e. they should:

- act as an early alert for emerging health issues and have predictive capability
- highlight current and significant health issues that require and will respond to priority action;
- cover issues that underlie a range of health problems and would be further elucidated by gender-based analysis;
- be based on sound empirical evidence in relation to health effects;
- be useful for monitoring performance and for evaluation of interventions;
- be measurable;
- be valid and reliable for general populations and for diverse population groups.

Where possible, indicators were selected from existing indicator sets including WHO gender and women's health units at AMRO/PAHO³, OECD and Health Canada. However, as previously mentioned, current sets of indicators failed to cover certain issues of great concern for women's health. For these neglected issues such as feminization of poverty and gender-based violence, indicators were either inappropriate or non-existent. For instance, with regard to poverty issues, it is now widely acknowledged that the "new" face of poverty is female. Yet there is no indicator available as the usual measurement of income or consumption to estimate poverty and data is not systematically sex disaggregated. Experts at the meeting indicated that having an index for "feminization" of poverty and women's control over own income would be helpful. Experts also raised the issue of gender-based violence

³ AMRO/PAHO 2003

and its underreporting. They mentioned that those working on this issue at the grassroots level hold records, but due to the sensitivity of the issue and the type of indicators used, the information collected may be considered biased, unreliable and inappropriate for national reporting. Representatives of civil societies were very keen on having better measures for monitoring and accountability purposes (WKC, 2004a) but also making use of those existing records. Finally, participants of the meeting identified characteristics of an optimal monitoring system to ensure that it takes place as a social process.

Consultative meeting

The consultative meeting was the last phase in reaching the consensus on the core set of leading health indicators. Again the list of indicators was reviewed along with their definitions to allow for international comparability. Data on health systems performance was perceived by the experts, and it was suggested to propose more indicators to ensure accountability of the local and national authorities. As a whole, seven new indicators to address issues in areas that were overlooked were suggested for further consideration (see annex 3). In addition to identifying a core set of leading health indicators, the experts identified the key features of a monitoring process to ensure that monitoring takes place as a social process. The last requirement was a validation through pilot testing described below. This would enable assessment of the technical feasibility of data gathering and the indicator's capacity to influence policies and programmes as well as to reduce the list to one of global core indicators.

Validation

Validation and pilot implementation was the final phase of consensus building. Several sites were proposed for testing. The sites were selected according to the recommendations of the experts meeting. Evident factors in selection were funding and political willingness. However, in order to reduce the list of indicators to a globally applicable core list, the core set of indicators had to be tested in sites of different socioeconomic and cultural backgrounds. Two sites were selected, Canada and China. These countries have not only very different cultural, social and economic settings but also differences in the level of data production. The China pilot started in 2004 and was conducted in collaboration with the Chinese Ministry of Foreign Affairs and the Rockefeller Foundation, with funding from the WHO Regional Office for the Western Pacific. The second pilot was conducted in Manitoba, Canada in collaboration with funding from WKC. The second pilot is completed and the findings are under review.

Outcomes

There were both tangible and intangible outcomes of this consensus building.

Out of each consultation came a different product, each of them complementing one another. First, out of the Tanzania meeting, a set of principles to guide the work was identified together with a first set of indicators. From the online consultation the list of indicators was further brought down to a more manageable number and finalized at an expert group meeting. The semi-final product was a core set of 36 leading health indicators:

- 12 on health status (including alternate indicators)
- 13 on determinants of health
- 11 on health and welfare systems performance

It was also possible to observe that throughout the process, participants felt empowered by gaining greater understanding of the concepts, built confidence on issues related to gender and women's health and have also expanded their networks.

Discussion

Reaching consensus refers to reaching general agreement or accord and not unanimity. Different platforms provide additional opportunities for dialogue. The Tanzania meeting was an initial strategic platform as it enabled significant participation of people from information-poor countries in Africa. It also provided an opportunity to express views, such as how the implementation of a core set of leading health indicators would be perceived in a country like the United Republic of Tanzania. This meeting contributed to the forging of a common understanding and framework for developing a set of principles to guide the work (annex 2). The principles constituted an initial basis for selecting the agreed set of leading health indicators.

The online consultation was a different type of consultation method. First it was limited to those who are familiar with IT tools. However, it provided a platform for broader consultation on the core set of indicators and enabled the participation of experts who did not attend the Tanzania meeting for time or cost constraints. Even though the online consultation was perceived as a useful mechanism to shorten the list of leading health indicators, it failed to achieve consensus through electronic voting.

The work towards finalizing the core set of leading health indicators progressed considerably at the expert group meeting. Due to the smaller number of participants it was also possible to discuss technical issues. In building the set of indicators, it was clear that the relevance of indicators may differ from one setting to another and that countries would have to review the

list based on their own context. However, the experts' list of leading health indicators was flexible to accommodate new data and refinement by countries.

Consultation is not a one-time activity and has to be sustained and takes place at the monitoring stage. Indicators are effective tools for awareness raising and pointers to areas that require further research. As discussed in the expert group meeting, the value of high-quality and conceptually sound indicators is limited if there is no appropriate monitoring system in place to track inequities and reduce inequity gaps, as well as the capacity to monitor indicators – quantitative and qualitative – that provide the evidence to support policy-making and operation and are pointers to emerging issues, be they health, social or economic. Indicators used for the purpose of monitoring key issues related to women's health have traditionally been limited to reproductive health and tend to be proposed by experts without necessarily taking into account the views of relevant stakeholders. Indicator development and utilization need to take place through a participatory process in order to ensure effective monitoring and social accountability of those involved in the process (WKC 2004).

Effective monitoring of equity trends can support policy development and "reforms". It is important that women themselves are involved in identifying health needs and priorities. If governments are to propose changes intended to have positive impacts on people's health, those involved in making these changes must understand the social context of these people, and act accordingly. For policies and programmes to translate into effective actions and induce positive changes, it is important to involve the views of the recipients, users and beneficiaries. Those involved in the process of selecting indicators, must ask the following questions before engaging in data collection:

- what information is needed and for what purposes?
- which issues should be given priority and why?
- who are the key stakeholders?
- are the indicators selected adequate measures for the concerned issues and reliable?
- how should the information be packaged to be raise awareness and inform policy?

Considerable investment is put on measuring health outcomes, rather than to respond to information needs at national, local and community levels. For monitoring to be effective, there should be adequate infrastructure for collection and collation

of valid and reliable data but monitoring should also be a social process through which the *raison d'être* of indicators is regularly reviewed, implications for action refined and decisions taken to effect greater equity. These findings support what was written by Lin and al. (2004).

An effective and efficient health information system would result in a health system that would be more responsive to people's health needs, and demand and fulfill its social accountability. Collecting data strictly on health is ineffective and may in fact be deleterious if used for governance equity priority-setting and policy formulation if the perspectives of the different stakeholders are not reflected. Experience has shown that the implementation of an information system as a vehicle for accountability requires organizational change within a framework of human resource development and technical support. Improving the health of a population requires that people concerned with women's health and gender issues including civil societies, academics and officials have the capacity to work together to build a database as a platform to address underlying differentials in health status within and between populations, and that they have adequate capacity. International agencies and governments – national or local – need to provide platforms to facilitate such collaboration among relevant stakeholders. Mechanisms to involve different stakeholders may be different depending on a country's context. However, if the ultimate objective is to improve the health of the population through more efficient health systems, involvement of key stakeholders is crucial.

Conclusion

The consensus over the gender-sensitive core set of leading health indicators was a relatively long and extensive process, which lasted almost two years. The consultation process was done through different mechanisms ranging from international meetings, online voting and expert group meeting. The core set of indicators was brought down to 34 leading health indicators and was pilot tested in two sites. Multiple stakeholders participated in the project such as government officials, representatives from civil societies and academia from different social, economic and cultural backgrounds.

The list of indicators is still considered relatively long. Therefore, countries wishing to use the set may need to further adapt the list to its own social and economic contexts.

The suggested list is considered a useful tool for policy and decision-making locally, nationally and globally.

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Annex 1
*Criteria for the selection of indicators*⁴

- 1) **Participation.** Indicators should wherever possible be collected in a participatory fashion, with input from all stakeholders. At the project level in particular, indicators should be developed in unison with intended beneficiaries.
- 2) **Relevance.** Indicators should be relevant to the needs of the user; they should fit closely with what the user is aiming to achieve.
- 3) **Disaggregation. All data should be disaggregated by sex.** This is a key point for the development of gender-sensitive indicators. Wherever possible data should also be disaggregated by age, ethnicity and socio-economic grouping.
- 4) **Comprehensibility.** Indicators should be easy to use and understand. Indicators should be developed at a level relevant to the institutional capabilities of the user; there is little point developing a complex system where there is limited social science expertise.
- 5) **Clarity of definition.** A vaguely defined indicator will be open to several interpretations, and may be measured in different ways at different times and places. For example, does the indicator *adoption of a new technique by a farmer* mean that he or she buys some fertilizer only once (if

so, how much?), or must the purchase be repeated (if so, how often and for how long?), and should the application of the new coverage be monitored (if so, over what period?) (Carvalho and White 1994). In addition, care must be taken in defining the norm or bench-mark implicit in any indicator. For example, in examining the status of women, is the norm the situation of men in a particular country, or is it women in other countries?

- 6) **The number chosen should be small.** There are no hard and fast rules to determine an appropriate number, but a rule of thumb is that the user should avoid two temptations:

- 1) 'information overload';
- 2) 'over-aggregation', that is, designing a composite index (such as UNDP's Human Development Index) based on aggregation and weighting schemes which may conceal important information and value judgements. In general, the number of indicators should be as small and disaggregated as possible, especially for new policy endeavours. Over time, after some experimentation, a larger set may be developed.

Where composite indexes are devised, the value assumptions of selection and weighting should be made explicit, and the disaggregated components should be readily available.

- 7) **Specificity.** The selection of indicators should stress the specific concerns of the project or program, and should reflect those things that the project intends to change.

⁴ Guide to gender-sensitive indicators (Beck 1997)

Annex 2

Guiding principles

- The work should build on existing systems, i.e. improve them and obtain new data by taking advantage of existing collection efforts;
- The work should build on indicators proposed through key international consensus, including the Millennium Development Goals (2000), the International Conference on Population and Development (1994), the Beijing Plan of Action (1995) and the Convention on the Elimination of All Forms of Discrimination against Women (1979);
- The data collection methods must be ethical for women;
- Recognize that data collection and analysis may need capacity building at country and community level;
- The need to improve the specificity of reporting at international level and the harmonizing of national reporting systems should be addressed;
- Conceptual clarity and soundness should be ensured, e.g. sex-disaggregated versus gender-sensitive indicators. Indicators should be identified as to whether they are meant to identify women's health or gender and health, or both;
- Where ideal indicators would add to the data collection burden, proxy indicators should be used and so identified;
- A life cycle approach should be incorporated extending beyond reproductive health issues and giving more emphasis to young people and older women;
- A core set of indicators should be used globally. Optional modules could also be developed that will allow for harmonization and comparison across peer countries and/or regions/cities;
- Aim for the ideal but seek to ensure commitment from governments and international organizations;
- Both quantitative and qualitative indicators should be reported on and national contexts explicitly taken into account in the reporting system;
- Benchmarks should be set for performance monitoring where possible

Annex 3

Tier 1: Health Status

- 1.1 Maternal mortality ratio
- 1.2 Low birth weight rate, boys and girls
- 1.3 Infant mortality rate, boys and girls
- 1.4 Mortality rate for ages 1–4 years, boys and girls
- 1.5 Life expectancy at age 65 years, by men and women (in some countries, in the absence of other data, life expectancy at birth may be used as an indicator)

- 1.6 Rate of self-rated depression, men and women
- 1.7 Rate of self-rated poor health, men and women
- 1.8 Rate of reported domestic violence
- 1.9 Rate of reported sexual violence, men and women, by age and relationship
- 1.10 Suicide rate, men and women, by age
- 1.11 HIV prevalence among men and women, by age
- 1.* A country-specific indicator

Tier 2: Determinants of Health

- 2.1 (a) Percentage of population with access to potable water, rural and urban (by men and women, if data available)
(b) Percentage of population with access to adequate sanitation (by men and women, if data available)
(c) Proportion of population using solid fuel (by men and women, if data available)
- 2.2 Literacy rate for population aged 15–24 years, men and women
- 2.3 Percentage of population living below national poverty line (A measure of feminization of poverty to be developed; The process should involve UNIFEM and World Bank)
- 2.4 Decision-making on own income
- 2.5 Percentage of regular smokers in population aged 15 years and over, men and women, by age
- 2.6 Proportion of population aged 15 years and over indulging in heavy drinking, men and women, by age
- 2.7 Prevalence of illicit drug use in population (particularly aged 15–24 years), men and women, by substance
- 2.8 Overweight and obesity, men and women, by age
- 2.9 Percentage of young people (aged 15–24 years) reporting using condom at last high risk sexual encounter, men and women
- 2.10 Contraceptive prevalence rate (particularly aged 15–49 years), men and women, by contraceptive
- 2.11 Access to safe abortion
- 2.12 Proportion of population aged 15 years and over receiving regular health examination within 12 months, by sex and age
- 2.13 Prevalence of anaemia in women
- 2.* A country-specific indicator

Tier 3: Health Systems Performance

- 3.1 Ambulance use (medical transport), men and women, by age (to be developed)
- 3.2 Rate of cataract procedure, men and women, by age
- 3.3 Use of medication for cardiovascular disease, men and women, by age

- 3.4 Percentage of births attended by skilled health personnel (excluding trained or untrained traditional birth attendants)
- 3.5 Proportion of health facilities that offer gender-sensitive patient-centred care (e.g. rape crisis centre, voluntary counselling and testing services for HIV) (to be developed)
- 3.6 Proportion of respondents (men and women) reporting being treated with respect (to be developed)
- 3.7 (a) Average waiting time for coronary interventions, men and women
- (b) Average waiting time in primary care for patient to see doctor, men and women
- 3.8 Proportion of men and women accessing provider type of choice
- 3.9 Percentage of population covered by insurance, men and women, by age and by gender-specific services (to be developed)
- 3.10 Out-of-pocket health expenditure, men and women
- 3.11 Not seeking or deferring care because of health-care cost, men and women
- 3.* A country-specific indicator

Annex 4

Consensus building processes for developing gendersensitive leading health indices

