DALYs and Reproductive Health:

Report of an informal consultation

27-28 April 1998
### Abbreviations

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tbody>
<tr>
<td>DALYs</td>
<td>Disability Adjusted Life Years</td>
</tr>
<tr>
<td>GBD</td>
<td>Global Burden of Disease and Disability</td>
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<tr>
<td>YLLs</td>
<td>Years of life lost</td>
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<td>YLDs</td>
<td>Years lived with a disability</td>
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<tr>
<td>ICD</td>
<td>International Classification of Diseases</td>
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<tr>
<td>ICIDH</td>
<td>International Classification of Impairments, Disabilities and Handicaps</td>
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<tr>
<td>ICPD</td>
<td>International Conference on Population and Development</td>
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1. INTRODUCTION

The informal consultation on ‘DALYs and Reproductive Health’ held at the World Health Organization (WHO), Geneva, 27-28 April 1998, provided an important opportunity to discuss the use of the Disability Adjusted Life Year (DALY) as a metric for the estimation of the burden of disease due to reproductive ill-health. The group of experts from 12 countries, were drawn from both reproductive health and measurement of disease fields (see List of Participants Annex 2).

The purpose of this report is to summarise these discussions, in particular:
- to clarify the value judgements and assumptions made in using the DALY metric to estimate the global burden of disease;
- to highlight major concerns and gaps in the 1990 Global Burden of Disease (GBD) analysis;
- to identify improvements for the GBD exercise for 2000, and
- to suggest further research to better capture the burden of reproductive ill health.

This document is, therefore, not a detailed critique of the DALY methodology as such, since ample literature already exists on this topic (Anand and Hanson 1997, Paalman et al 1998 among others). Rather it represents an analysis of the difficulties inherent in estimating the GBD due to reproductive health conditions using the DALY methodology.

The first section provides the Background to the meeting. It includes the rationale for and objectives of the meeting, and a short introduction to DALYs, their development, and their use within the GBD Study. The GBD study was designed to promote greater consistency between data derived from different sources and to decouple reality from advocacy on the part of different disease-based programmes, each of which tends to claim more than its fair share of total mortality and morbidity. DALYs are the measurement unit for the GBD study and must, therefore, be viewed within this context. It should be stressed that DALYs and the overall burden of disease study are not synonymous. The distinction between the two is important and one that is often not appreciated.

Since this consultation focused on issues related to the DALYs and reproductive health in particular, there follows a brief discussion on what is reproductive health, how much burden of reproductive ill health the DALYs actually capture, and the barriers to measuring this in the 1990 GBD study.

Any discussion on DALYs must clearly differentiate between their two key functions:
1. the ‘positive’ exercise of measuring the burden of disease, and
2. the ‘normative’ exercise of resource allocation.

This consultation focused primarily on problems relating to the former. Therefore, the body of this report considers how DALYs can better measure the burden of reproductive ill health, concentrating on the following areas:
- the epidemiological database
- valuing health states
- capturing the gender dimension of burden.

The use of DALYs as a tool for priority setting, was also debated. It was stressed that the DALY metric is designed to assist cost-effectiveness analysis, but that clearly any single outcome measure will have serious limitations as only a restricted number of dimensions of health and populations can be taken into account. Participants expressed concern that the methodology may reinforce a medical model of health care and narrow ‘vertical’ approaches. Thus, it was repeatedly stressed that DALYs should not be used as the only tool for prioritisation or resource allocation but should be assessed along with criteria such as issues of justice and equity, human rights, community preferences etc.
Finally, with a revision of the GBD study planned for 2000, and the application of DALYs in national burden of disease studies in a number of developing and developed countries, it is crucial to set out recommendations for improving the DALY and the overall GBD methodology better to capture the burden of reproductive ill health. This consultation was a first step to soliciting the active involvement of a variety of players, towards achieving this aim. The conclusions and recommendations contained in this report summarise the main problems, research needs and next steps, identified at this consultation, to improve on the DALY exercise.
2. BACKGROUND

2.1 Rationale

The DALY methodology clearly represents an advance on earlier measurement techniques to assess the overall burden of reproductive ill health. It permits us for the first time to count the burden resulting from both deaths and disability. However, some experts have voiced concerns that the method fails to capture the full scope of reproductive health problems. These concerns have implications for the use of DALYs, especially as a basis for public-health policy and resource allocation, in light of the very limited data on the incidence and prevalence of reproductive ill health.

With a revision of the GBD study planned for 2000, and the application of DALYs in national burden of disease studies in a number of developing and developed countries, continued debate and refinement of the approach, as well as clear recommendations to better capture the burden of reproductive ill health are essential. This consultation was a first step to soliciting the active involvement of a variety of players, towards achieving this aim, and its main objectives were as follows:

2.2 Objectives of the consultation

*Overall Objective*

To bring together expertise in DALYs and in reproductive health, in order to encourage open discussion on how the DALYs were calculated and to evaluate the DALY methodology with regard to the measurement of the global burden of disease due to reproductive ill health.

*Specific Objectives*

- To review the available evidence on the incidence and prevalence of reproductive ill-health.
- To evaluate the methodology for estimating DALYs, including disability weights as applied to reproductive health conditions.
- To discuss issues related to the calculation of the burden of disease in local settings, in particular, the valuation of health states by disadvantaged women.
- To identify next steps and research needs.

2.3 The development of the DALY and links to the GBD

A main objective of this consultation was to encourage open discussion and clarity on how the DALYs estimates were actually derived. Christopher Murray, responsible for the 1990 Global Burden of Disease Study, gave an introduction to the study and the development of the DALYs; in particular the reasoning behind the value choices made and their implications for measuring the burden of reproductive ill health. Here, we provide a brief overview of the GBD study, in particular how the DALYs are derived, and highlight some general reservations that emerged during the discussions regarding the approach.
Initiated in 1992, the GBD study was conducted, at the request of the World Bank and in collaboration with WHO, to quantify the burden of disease and injury on human populations. Quantification requires a unit of measurement, which for the GBD was the DALY.

The GBD study was conducted in response to the need for a clear assessment of the relative magnitude of diseases and injuries, and the proportion of these attributable to major risk factors or socio-economic determinants. This information was felt to be indispensable for a variety of purposes including the identification of major health problems and their relative magnitude; the recognition of patterns of health problems and the search for explanations of these patterns; the prioritization of health research investments; and along with other information, the allocation of health resources across different health interventions (Murray and Acharya 1997).

The GBD study set out to address three primary goals:
• to infuse information about non-fatal health outcomes into debates on international and national health policy;
• to disentangle epidemiology from advocacy in order to produce consistent assessments of the disease burden; and
• to measure disease and injury burden in a way that can also be used to assess the cost-effectiveness of interventions. The DALY was proposed for this purpose.

2.4 What are DALYs and how are they measured?

DALYs (Disability Adjusted Life Years) are a time based indicator of health outcome, that are composite measures of the overall burden of disease due to losses from premature death and non fatal disability. For the DALY calculations, diseases and injuries, and their sequelae were classified, according to 107 causes of death and 483 disabling sequelae, on the basis of the International Classification of Diseases - Ninth Revision (ICD9). 

To determine the number of years of life lost due to premature mortality all deaths in 1990 were assigned a disease category and grouped by age, sex and demographic region. This was based on death records where available, and 'expert judgement' where not. The number of healthy years of life lost (YLLs) were then estimated, based on the differences between the actual ages at death and an ideal standard life expectancy at those ages. The standard life expectancy used was 82.5 years at birth for women, and 80.0 for men for all countries irrespective of current life expectancy calculations. A difference of 2.5 years between males and females was selected to represent the 'potential true biological difference' (Murray and Lopez 1996).

For disability, the incidence of cases by age, sex and demographic region was estimated on the basis of community surveys or, where that was not available, 'expert opinion'. The

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1 Annex Table 2 (Murray and Lopez 1996)
2 Annex Table 6 (Murray and Lopez 1996)
3 Annex Table 7 (Murray and Lopez 1996)
number of years lived with disability (YLDs) were then obtained by multiplying the expected duration of the disability (to remission or to death) by a disability weight that measured the severity of the disease compared with death. Seven disability classes were defined, and a weighting agreed upon by experts, between perfect health (0) and death (1), represented the severity of each disablement.

Severity weights were assigned to each of the 483 disabling sequelae using a two step process. First, 22 conditions were selected to encompass a wide range of disability severities and different health states. A group of 12 health professionals, (60% male, 40% female) from around the world, then assigned weights to these conditions by person-trade off methods. (Nord 1992) The person-trade off methodology requires an individual to choose between curing a certain number of individuals in one disability class versus another number in a different class. The methodology elicits the point at which the individual is indifferent between the two choices being offered. At this point the outcomes are equivalent and a weight is derived (Murray 1994). When making their assessments, individuals were asked to evaluate, ‘the average individual with the condition described taking into account the average social response or milieu’. These weights were then arbitrarily divided along the spectrum from perfect health to death, into seven disability classes. Next, the remaining 461 conditions and sequelae were categorized into the same seven classes by expert opinion.

Therefore, for a specific population group, the total unweighted number of DALY’s lost due to a specific disease is:

1. time lost due to premature death = expected life time - age at death
2. time lived with a ‘disability’ = duration of the disability x severity weighting

In producing the final set of DALY figures two further steps were required. Firstly, weights were attached to DALY’s lost at different ages. A modified Delphi method was used with a group of public health experts to ascertain a continuous age weight function; that is the value of each year of life lost rises steeply from zero at birth to a peak at age 25 and then declines with increasing age (Murray 1994). Thus, a year of young or middle-aged adult life is valued higher than that of young children or the elderly.

Then, a yearly discount rate of 3% was used so that future years of healthy life were valued at progressively lower levels. Using a rate of 3% means, for example, that one year of healthy life is counted as approximately half a year if it occurs 22.5 years from now, and only as 3 months if it occurs some 45 years into the future. The arguments for and against discounting are summarised elsewhere, however, three percent is noted as, ‘the lower limit of acceptability for those economists who are persuaded by opportunity cost arguments and is the upper limit for public health practitioners who are willing to accept a positive discount rate’ (Murray and Lopez 1996).

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4 Annex Table 8 (Murray and Lopez 1996)
5 Annex Table 3 (Murray and Lopez 1996)
6 Annex Table 9 (Murray and Lopez 1996)
7 p44-54 (Murray and Lopez 1996)
Given these various inputs into the DALY formula and GBD calculations; namely the selection of mortality causes and disabling conditions, data estimations, and social value choices, how do the final calculations convey or represent the true burden of disease, in particular the burden of reproductive ill health? This was a key theme addressed at the consultation and is discussed below.

2.5 The concept of reproductive health

Carla AbouZahr introduced the concept of reproductive health as defined at the International Conference on Population and Development (ICPD) in Cairo, 1994. Reproductive health is defined in the Programme of Action as:

"... a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity, in all matters relating to the reproductive system and to its functions and processes. Reproductive health, therefore, implies that people are able to have a satisfying and safe sex life and that they have the capability to reproduce and the freedom to decide if, when, and how often to do so. ... It also includes sexual health, the purpose of which is the enhancement of life and personal relations, and not merely counselling and care related to reproductive and sexually transmitted diseases."

Reproductive health matters to everyone, but the issues it encompasses are different in men and women and change over a person's lifetime. Reproductive health is about behaviours and relationships, as well as health and ill health, and covers a vast menu of conditions. These range from conditions clearly related to reproduction such as pregnancy related mortality and morbidity; to conditions associated with sexual behaviours such as sexually transmitted diseases including HIV/AIDS; and conditions related to the reproductive organs such as endogenous reproductive tract infections. Diseases such as cancer of the cervix are clearly part of this menu. But, there are other issues that should be taken into account such as female genital mutilation, violence related to sexual behaviour - rape, sexual abuse, forced sex - and associated mental ill health. Finding out about reproductive health, therefore, means delving into intimate aspects of life which are everywhere bound by rules and regulations, traditions and taboo. It is often said that the three aspects of life most difficult to discuss openly are sex, birth and death: reproductive health must deal with all three.

Bearing in mind this rather daunting menu, how effectively does the DALY methodology capture the burden of reproductive ill health? In addressing this issue it is important to bear in mind that the DALY was developed for the GBD exercise during the early 1990s, before the concept of reproductive health was fully articulated at ICPD in 1994, and uses ICD9 to classify diseases. This poses particular problems for measurement since reproductive health cuts across the lines along which diseases have traditionally been classified, and deals with both diseases and with normal physiological processes.

2.6 Capturing the burden of reproductive ill health

Carla AbouZahr introduced the discussions by noting that the DALY methodology and its application to estimate the global burden of disease in the 1993 World Development Report represented a substantial improvement on earlier quantification attempts, and brought reproductive health more prominently on to the global health and development agenda.
According to DALY estimates in the 1990 GBD study, reproductive ill health accounted for 22% of the global disease burden among women of reproductive age (15-44), and 3% for men. In sub-Saharan Africa reproductive ill health was particularly significant, and accounted for 40% and 9% respectively (see Table 2). Maternal conditions dominated the burden of reproductive ill health, particularly in areas where this burden was highest, for example Sub-Saharan Africa and India.

Reproductive health also has substantial inter-generational effects; poor reproductive health and lack of access to adequate care for the mother is reflected in poor birth outcomes in the infant. Thus, if perinatal causes are added, some 10% of the total DALYs lost can be ascribed to reproductive ill health - all ages and both sexes combined (see Table 1). However, perinatal conditions do not generally fall on the same individuals as those due to other aspects of reproductive ill health.

<table>
<thead>
<tr>
<th>Table 1: Burden of reproductive ill health, 1990 (% total burden)</th>
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<td>- includes reproductive and perinatal conditions</td>
</tr>
<tr>
<td>World</td>
</tr>
<tr>
<td>India</td>
</tr>
<tr>
<td>Sub-Saharan Africa</td>
</tr>
<tr>
<td>Middle Eastern Crescent</td>
</tr>
<tr>
<td>Latin America and the Caribbean</td>
</tr>
<tr>
<td>Other Asia and Islands</td>
</tr>
<tr>
<td>China</td>
</tr>
<tr>
<td>Formerly Socialist Economies of Europe</td>
</tr>
<tr>
<td>Established Market Economies</td>
</tr>
</tbody>
</table>

Source: Murray and Lopez (1996)

The DALY calculations relied heavily on evidence about maternal mortality, at the expense of other aspects of reproductive ill-health. This bias towards maternal conditions and the relative neglect of other conditions (with the exception of STDs and HIV/AIDS) was particularly relevant when the burden of disease is assessed in settings where maternal mortality is relatively low. Once the contribution of maternal and perinatal conditions has been reduced, reproductive ill-health tends to fall low down in the scale of disease burden, see for example Established Market Economies and China. Thus, a main concern at the consultation was to highlight areas of reproductive health neglected in the 1990 GBD study (see section 3.5).

In the discussions on the extent to which these figures convey or represent the true burden of reproductive ill health some barriers to using the DALYs methodology were raised. These are related to both the conceptual underpinnings and technical aspects of the methodology, and are summarised below.
2.7 Problems in measuring the full burden of reproductive ill health

• What is the actual ‘burden’ being measured?
The ‘burden’ of disease as defined by Murray is a measure of ill health reflected by functional limitations and premature mortality, and is adjusted for age, sex and time of onset of illness (Anand and Hanson 1997). It is based on the decision to take account of disability rather than handicap; disability being defined as ‘any restriction or lack of ability to perform an activity in the manner or within the range considered normal for a human being’ rather than handicap which is, ‘a disadvantage for a given individual resulting from an impairment or a disability that limits or prevents the fulfilment of a role that is normal (depending on age, sex and social and cultural factors) for that individual’ (International Classification of Impairments, Disabilities and Handicaps, ICIDH, WHO). Thus, in practice this indicator appears to be closer to the aggregate ‘quantity’ of ill health, since it excludes socioeconomic, cultural and environmental factors which are likely to have a significant impact on the overall ‘burden’, and people’s differential ability to cope with that burden. Disability is a more restrictive interpretation of burden that what participants felt that the notion of burden actually connotates. For example, class 5 ‘severe disability’, is defined as ‘needs assistance with instrumental activities of daily living such as meal preparation, shopping and housework’. This is assumed to have the same meaning to the individual irrespective of the social situation. Many conditions involve discomfort, pain, suffering, stigma, or social or economic consequences that are not explicitly incorporated in the DALY. Examples include the social and economic (as opposed to the physical) consequences of obstetric fistula or infertility.

• Measuring the ‘burden’ for whom?
By focusing on the performance of the individual suffering from the condition, the burdens which fall on households, and on larger communities are not included. For example a man’s infertility may have implications for his wife’s economic and social well being.

• Estimating the burden of disease for women
Using an ultimate ‘ideal’ difference in life expectancy of 2.5 years (based on biological differences), the DALY methodology may understate the disease burden of women relative to that of men. This ‘ideal’ gap is considerably smaller than the observed gender gap in low mortality populations, for example Japan’s is 6 years, factoring out the effects on life expectancy of males’ greater exposure to social and other risk factors. This may have important implications for the estimation of the disease burden of women compared to that of men. The smaller the gender gap, the smaller will be the female contribution to the burden of disease relative to the male contribution. Thus, if the true biological gap is greater than 2.5 years, then the GBD will understate the disease burden of females relative to that of males. On the other hand, the notion of equity would argue for having the same “ideal” life expectancy for men as for women.

• Valuing health states - whose perspective?
In reproductive health, as perhaps in no other aspect of health, people’s own perceptions of health and disease and the value they put on different health states may differ from what the clinician diagnoses or the epidemiologist investigates. What can appear trivial from a clinical perspective may have profound consequences for the health and well being of the individual. Thus the use of experts, rather than populations or patients, for valuing health states has been queried since they do not necessarily reflect how individuals or society judge the seriousness of different health conditions.
Another related concern is the lack of understanding of concepts of disability in different cultures. The DALY approach does not allow for any differences in disability severity related to social, cultural or economic contexts. However, when developing internationally comparable estimates of burden of disease, one uniform set of standards may, in practice, be necessary.

- **Measuring interaction between duration and severity of disability**
  The DALY as used in the GBD does not capture the difference in utility loss for an individual due to a temporary or permanent functional loss beyond differences in time lives with the problem. The incapacity, for example, of not being able to walk naturally for a short time period due to a broken ankle, or not being able to walk naturally for the rest of your life due to an amputated leg, bear different utilities (Paalman et al 1998). It can also be argued that some disability conditions are worse than death. The method does not allow for this.

- **Gaps in reproductive health conditions covered**
  Using ICD9 as the starting point, some conditions and sequelae were not counted among the 107 causes of death and disease and the 483 sequelae. The neglected aspects of reproductive ill health, identified at the consultation, are summarised in Table 4. Thus the 1990 GBD study estimates under-represent the total burden of death and disability associated with reproductive ill health and possibly with other disease-specific clusters as well. Only the five direct obstetric complications that result in maternal death were taken into consideration in estimating disability along with estimates of the prevalence of major STDs (Syphilis, Gonorrhoea, Chlamydia), HIV/AIDS and reproductive cancers (see Table2 and Table 3).

- **Lack of epidemiological data on reproductive conditions**
  The paucity of information about the dimensions, causes and consequences of much reproductive ill health was not adequately accounted for and inevitably lead to its neglect in the DALY calculations. Obstetric, gynaecological and contraceptive morbidities are particularly problematic to measure and were thus almost entirely omitted from the calculations.

- **Uneven coverage of data**
  This is particularly problematic for morbidity data generally, and mortality data for Africa. For example, in the 1990 GBD study, estimates of mortality for Sub-Saharan Africa are explicitly based on an extrapolation from the 1% of the population covered by vital registration in the Republic of South Africa (Cooper et al 1998).

- **Attribution of ill defined cause of death**
  In most developing countries (and many developed ones too) the quality of the epidemiological data does not permit consistent and complete attribution of cause of death. As a result ill-defined causes of death can account for a large share of deaths (Murray and Lopez 1996). In the 1990 GBD study reported deaths classified as ill-defined were assigned to communicable diseases if they occurred in children below the age of 5 and to non-communicable diseases if they occurred in older age groups. As a result many deaths due to STDs and AIDS may have been misclassified to the non communicable disease category.

- **Neglecting cumulative morbidity**
  The DALY's methodology tends to neglect the interdependence of diseases and conditions and this can be particularly problematic for conditions related to sexuality and reproduction. Thus, some pre-existing conditions that can be aggravated by pregnancy (diabetes, malaria,
cardiovascular disease, helminth infestation, tropical diseases, depression) are not adequately accounted for.

- **Ignoring the existence of co-morbidity**
  If an individual simultaneously has more than one condition each with a disability weight, this could lead to a nonsensical situation where the individual's disability weight is greater than 1; that is greater than death itself. Thus, in most cases, co-morbidity was not allowed.

- **Inability to account for the burden associated with stillbirths**
  By definition, no individual can have any expectation of healthy life until the moment of live birth; stillbirths are therefore not counted as adverse outcomes either for perinatal conditions or for the mother, unless the still birth is associated with a maternal condition such as obstructed labour and thus counted for the mother. This could be dealt with either from the fetal point of view - that is giving it a lost life expectancy of x, or it could be valued from the parental perspective. Whatever the decision made, there are sensitive issues to be taken into consideration that go beyond the technicalities of estimating DALYs.

- **Problematic age breakdowns used in the GBD study**
  The age groups used for deaths in the GBD study, 0-4, 5-14, 15-29, 30-44, 45-59 may cause problems with comparing data and when examining the burden of reproductive ill health since reproductive age is usually defined as aged 15-49. Furthermore, a number of conditions that should be measured as reproductive ill health occur at younger ages, for example FGM, and many young people below age 15 are sexually active, either voluntarily or involuntarily.

Detailed discussion at the consultation focused on three broad areas related to the above:
1. the epidemiological database
2. valuing health states, and
3. capturing the gender dimension of the GBD

Discussion concentrated on ways of improving the DALYs approach in these areas, specifically identifying the main gaps, the research required and the next steps.
3. THE EPIDEMIOLOGICAL DATABASE

Many barriers to measuring the full burden of reproductive health, using the DALYs approach, are related to the availability and quality of the underlying epidemiological data. The paucity of information about the dimensions, causes and consequences of much reproductive ill-health leads inevitably to the possibility of bias and other errors in the DALY calculations. Thus, one of the main conclusions of the consultation was that the single most important way to better capture the burden of sexual and reproductive ill-health is through re-examining the empirical evidence.

However, it is also important to remember that the DALY metric is not a prerequisite to measuring the burden of disease; the prevalence and incidence of a condition alone is powerful information. Thus, improving the epidemiological database, through improved vital statistics and other national and local data mechanisms is crucial in itself, while also being a fundamental precursor to using the DALY methodology.

This consultation went a first step to addressing this issue, firstly through identifying areas which had been previously neglected and detailing a composite list of reproductive health conditions that should be covered as the starting point. Next discussion turned to what is known; what was missed in the previous exercise and what has become available since. Although, data on reproductive mortality and morbidities in developing countries is generally weak, greater efforts at identifying and compiling such information, and making it available to a broader audience, would be extremely valuable. Finally, an attempt was made to identify major data gaps, and areas requiring further research were flagged.

3.1 Range and quality of data used in GBD study

For the GBD study, global and regional cause-specific mortality and morbidity by age and sex was estimated for diseases or injuries for 1990, coded according to the ninth revision of the International Classification of Diseases. The fragmentary and biased coverage, and poor quality of much of the data made it necessary to use a combination of data sources and approaches to overall mortality and morbidity in general in the eight regions, not only that related to sexuality and reproduction.
Table 2  Total DALYs lost due to reproductive ill-health in women and men of reproductive age (as % total DALYs in the 15-44 year age group)

<table>
<thead>
<tr>
<th>Condition</th>
<th>Women (15-44)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>World</td>
</tr>
<tr>
<td>STDs excl HIV</td>
<td>4.23</td>
</tr>
<tr>
<td>Syphilis</td>
<td>0.22</td>
</tr>
<tr>
<td>Chlamydia</td>
<td>2.95</td>
</tr>
<tr>
<td>Gonorrhoea</td>
<td>1.06</td>
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<tr>
<td>HIV</td>
<td>1.78</td>
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<td>Haemorrhage</td>
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<td>Hypertensive</td>
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<td>Obst labour</td>
<td>3.18</td>
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<tr>
<td>Abortion</td>
<td>2.49</td>
</tr>
<tr>
<td>Reproductive cancers</td>
<td>1.42</td>
</tr>
<tr>
<td>Total reproductive conditions</td>
<td>21.90</td>
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Source: Murray and Lopez (1996)
<table>
<thead>
<tr>
<th>Latin America + Caribbean</th>
<th>World</th>
<th>Est. Market Econ.</th>
<th>Sub-Saharan Africa</th>
<th>Former Socialist Econ</th>
<th>India</th>
<th>China</th>
<th>Other Asia + Islands</th>
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<td>3.97</td>
<td>1.09</td>
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<td>1.79</td>
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<td>3.72</td>
<td>0.11</td>
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<td>0.02</td>
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<td>0.94</td>
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<td>0.04</td>
<td>1.82</td>
<td>0.15</td>
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<td>1.06</td>
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<td>0.02</td>
<td>0.02</td>
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<tr>
<td>16.80</td>
<td>3.12</td>
<td>4.20</td>
<td>8.54</td>
<td>0.41</td>
<td>2.93</td>
<td>0.06</td>
<td>2.30</td>
<td>0.51</td>
<td>4.25</td>
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</table>
Estimates of cause-specific mortality were based on vital registration data (where available), on epidemiological transition modelling for the broad groups, or on epidemiological estimates by disease experts for the specific causes. For some regions, cause specific mortality rates had to be proportionally reduced, in order for the sum of them to accord with total national mortality (Paalman et al 1998). General differences in data sources to estimate mortality are outlined below:

- Market economies and formerly socialist economies of Europe - vital registration data
- China - disease surveillance points, a sample registration system
- India - urban patterns based on vital registration data for one state; rural areas based on a verbal autopsy sample registration system of selected primary health centres nationwide, supported by specific follow up studies
- Latin America, the Caribbean, other Asia and islands, the Middle Eastern Crescent and sub-Saharan Africa - some vital registration data, but in most places deaths are not recorded or medically certified; epidemiological estimates; and estimates based on cause of death models in residual areas without data.

Compared to the challenges of estimating patterns of mortality by cause, the difficulties of quantifying non-fatal health outcomes by cause are even greater. In all respects, the definition and measurement of non-fatal health outcomes are less precise than for mortality. Even the general magnitude of the problem is much better known for mortality since decades of research and development of demographic estimation methods and models have led to reasonably robust estimates of the total number of deaths by age and sex in various regions. For morbidity, reliable information is required about the incidence of disease and injury, about the likelihood of incurring sequelae, and about their severity and duration. Unfortunately, very few datasets of this type exist. The data and information sources used in the GBD study, therefore, include health services data, disease and injury registries, community based research and cross-sectional surveys. Most of these estimates are less certain than mortality estimates and are likely to have large confidence intervals. The degree of uncertainty varies from disease to disease, and between age groups and regions.

### 3.2 Measuring reproductive morbidity

Existing research tells us little about the real prevalence of reproductive morbidity in communities worldwide, and its measurement is particularly problematic. Recent population based surveys have questioned the usefulness of self reported illness when compared with clinical or laboratory observations (Ronnsmans et al 1997). Therefore, facility based sources of data are being reconsidered and efforts are being made to assess and improve their quality and interpretation (Filippi et al 1998). In addition, self-reported data may provide different information than morbidity, such as on the quality or experience of an illness.

Below, we summarise the particular measurement problems highlighted at the consultation. However, before describing these, there are two points worth emphasising concerning DALYs and the quantification of non fatal health outcomes. For the DALY calculations diseases were classified on the basis of ICD9. This is fundamentally problematic since starting from a vertical disease orientation leads to the grouping together of diseases in terms of related pathologies and organ systems rather than according to epidemiological patterns, determinants, risk factors and consequences. This presents problems for attribution, for example, cancer of the cervix in terms of aetiology is closer to a sexually transmitted disease.
than to other cancers such as lung cancer. Yet in the DALY calculations it is listed under malignant neoplasms.

Secondly, DALYs do not measure acute events. A condition needs to have a duration of some time to be reflected in the DALYs, and consequently an understanding of its sequelae is required. The measurement of disability, therefore, requires not only data on incidence and prevalence by sex and region, but also on age at onset of the condition, its duration and severity. In reproductive health, many conditions that contribute to burden are actually short time-based physical events such as abortion or miscarriage and the longer lasting burden of psychological, social or economic consequences, are not valued.

Some problems associated with measuring reproductive morbidities

- **Definition is unclear**
  Of primary concern is the lack of clarity in defining reproductive morbidity itself, since the concept and its subtypes (maternal/obstetric, gynaecologic, contraceptive) are not clear cut (ICD9 definitions are given in Annex 1). The subcategories of reproductive morbidity overlap both conceptually and in their consequences for women and their clinicians.

  Morbidity may also be viewed from a number of dimensions; etiology, severity, duration, time of onset, accumulation and sequelae (Fortney 1995), which can interact producing a cyclic as well as a life-span effect. This cyclic and interacting nature of reproductive morbidity tend to complicate its definition further.

- **Possibility of detection bias**
  Detection bias refers to the variation in the likelihood that a condition will be diagnosed. There is, for most diseases, considerable variation in the likelihood of detection. The basic problem is that there are no ‘gold standards’ by which to diagnose the majority of reproductive morbidities.

- **The measurement trap**
  Reproductive health conditions can be subdivided into three types: those that can be measured both by asking people suffering from the condition and also by independent clinical or laboratory tests (fistulae, symptomatic STDs, advanced cancers of the genital tract); those that are asymptomatic and require clinical and/or laboratory tests for their identification (many STDs in women, subclinical prolapse); those that can be identified only by individual reports (dyspareunia) (Murray and Chen 1992).

  Participants shared research experiences of the past few years which demonstrate that reproductive morbidities are unlikely to be readily identifiable by simply asking respondents about signs and symptoms. For women especially, many conditions may remain asymptomatic and the effects apparent only many years later when extensive damage has already been done. At the same time, some conditions can only be identified by direct questioning. Thus, while three methods of diagnosis exist, many conditions may only be diagnosed by one on these, creating problems in terms of validation.

  These problems contribute largely to the universal lack of quality data on the incidence and prevalence of reproductive morbidity. However, as a next step the consultation set out to identify what information does exist.
3.3 What data exist?

A void in vital health information still exists for large parts of the global population. For the many people living in the world’s poorest countries, where the burden of disease is highest, often no count is made of those who are born or those who die. And, the absence of information on these two fundamental life events is just the tip of the iceberg: beneath the surface, reliable rates and trends in age, gender and social variations in ill health remain obscured from view. This gulf in population based information constitutes a major longstanding constraint to articulating effective policies and programs to improve the health of the poor and, as such, perpetuates profound inequities.

In the area of reproductive health, data on the incidence and prevalence of specific conditions are far from universally available although much has changed in the quite recent past. Monitoring and surveillance systems have improved in scope and coverage and community based research has broadened the knowledge base. Only a decade ago, little was known about the extent of pregnancy related mortality; today estimates are available for most countries. At the start of the HIV/AIDS pandemic, monitoring incidence and prevalence seemed an impossible challenge; today many countries have established the vital surveillance systems we need. At the same time, knowledge about the burden of disease caused by other sexually transmitted diseases - gonorrhoea, syphilis, chlamydia - has increased dramatically. Slowly the epidemiological data about cancers of the reproductive organs - cervix, breast, uterus, prostate - is beginning to accumulate. And a start has been made on documenting the dimensions of ill-health resulting from harmful practices such as female genital mutilation.

Yet there remain vast areas about which little is known. The burden of disabilities resulting from pregnancy-related complications remains poorly documented and measured. While there have been a large number of hospital based studies, these give little indication about the incidence and prevalence of conditions at population level. A huge toll of needless suffering is caused by reproductive tract infections, but as yet there is no means by which to measure this at population level. There is a growing awareness of the importance of the mental as well as the physical ill-health and suffering associated with sexual abuse and violence but again, there is no way of quantifying this burden. Also there is no means of capturing the positive aspects of reproductive health. The contraceptive prevalence rate, for example, while easily measurable and long used to demonstrate improvements in reproductive health, is in reality a poor reflection of the benefits (health and non-health) that accrue from avoiding unwanted fertility.

Thus, while much is still not known, it seems there are many useful sources of information on the epidemiology of specific conditions that were not utilised in the last GBD exercise.

3.4 Improving the use of existing data sources

The basic epidemiological data that are used to calculate prevalence and incidence are the most critical inputs to the approach and the most readily improved. But, as mentioned above, there is still a long way to go in terms of improving the basic data upon which the DALY is constructed. The African region is, perhaps, the least well-served in terms of the availability of sound, population based data. During the consultation, there was general agreement that increased efforts would be needed to improve data availability and thus avoid reliance on complex extrapolations, adjustments, weighting and assumptions about the incidence and
prevalence based on experiences in other regions, small sub-national populations and health facility reports.

At the same time, participants injected a healthy dose of realism into the discussions. Additional funding for large-scale epidemiological surveys is unlikely to become available, despite the increased attention to reproductive health following the International Conference on Population and Development which took place in Cairo in 1994. One way of generating the needed data will be to make better use of what is already collected but generally inadequately exploited. A number of population surveillance projects in Africa and Asia, for example, Matlab - Bangladesh, Novrongo - Ghana are currently collecting a vast range of information, much of it directly related to reproductive health. In sub-Saharan Africa alone, the INDEPTH network links 29 sites in 14 countries with a total of 1.1 million individuals under surveillance (Binka 1998). Making better use of these sources of data could represent a major achievement and help fill some of the gaps in our knowledge about the extent and nature of sexual and reproductive ill health.

Thus, greater efforts at identifying and compiling such studies and other routinely collected information, and making them available to a broader audience, would be extremely valuable. Also information that has been collected could be made more useful by encouraging the publication and dissemination of age and sex specific results in all cases. These were two specific recommendations made at the consultation that were added to the list of next steps to improve the GBD exercise for 2000.

3.5 **Neglected areas of reproductive health**

Using ICD9 as a starting point, poses particular problems for measurement since reproductive health cuts across the lines along which diseases have traditionally been classified, and deals with both diseases and with normal physiological processes. Therefore, many reproductive conditions and their sequelae were not counted in the GBD study, and the 1990 estimates under-represent the total burden associated with reproductive ill health. Earlier sections of this report have already outlined the concept of reproductive health and the DALYs lost due to reproductive ill health by condition (see Table 2). The major elements of reproductive ill health covered, including the diseases and sequelae as classified in ICD9, are outline in Table 3 below.

Only the five direct obstetric complications that result in maternal death (haemorrhage, sepsis, hypertensive disorders, obstructed labour, abortion) were taken into consideration along with estimates of the prevalence of major STDs (syphilis, gonorrhoea, chlamydia), HIV/AIDS and reproductive cancers.

Participants at the consultation took a composite list of reproductive health conditions as the starting point and highlighted previously neglected areas, and areas that should be reassessed in light of improved information. They also recommended that the next steps should include a more comprehensive assessment of what should be included next time, taking account of the suggestions below and data availability.

The DALY methodology excludes all indirect obstetric complications, which have been estimated to cause 20% of all maternal deaths or more (WHO 1994). Thus the consultation recommended that causes of maternal death be revisited looking particularly at these indirect
causes. Here we come back to the problem of the DALYs neglect of the interdependence of diseases. This causes some pre-existing conditions that can be aggravated by pregnancy (diabetes, malaria, cardiovascular disease, helminth infestation, tropical diseases, depression) to be insufficiently covered.

Table 3: Reproductive diseases and their sequelae included in the GBD study, 1990

<table>
<thead>
<tr>
<th>STDs excluding HIV</th>
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<tr>
<td>Syphilis -</td>
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<tr>
<td>- Congenital syphilis</td>
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<tr>
<td>- Low birth weight</td>
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<tr>
<td>- Primary</td>
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<tr>
<td>- Secondary</td>
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<tr>
<td>- Tertiary (cardiovascular)</td>
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<td>- Tertiary (gummas)</td>
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<td>- Tertiary (neurologic)</td>
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<tr>
<td>Chlamydia -</td>
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<tr>
<td>- Ophthalmia neonatorum</td>
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<tr>
<td>- Low birth weight</td>
<td></td>
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<tr>
<td>- Corneal scar (blindness)</td>
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<td>- Corneal scar (low vision)</td>
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<tr>
<td>- Cervicitis</td>
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<tr>
<td>- Neonatal pneumonia</td>
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<tr>
<td>- Pelvic inflammatory disease</td>
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<tr>
<td>- Ectopic pregnancy</td>
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<tr>
<td>- Tubo-ovarian abscess</td>
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<tr>
<td>- Chronic pelvic pain</td>
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<td>- Infertility</td>
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<tr>
<td>- Symptomatic urethritis</td>
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<td>- Epididymitis</td>
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<td>- Stricture</td>
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<tr>
<td>Gonorrhoea -</td>
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<tr>
<td>- Ophthalmia neonatorum</td>
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<td>- Low birth weight</td>
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<td>- Cervicitis</td>
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<td>- Ectopic pregnancy</td>
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<td>- Tubo-ovarian abscess</td>
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<td>- Chronic pelvic pain</td>
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<td>- Symptomatic urethritis</td>
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<td>- Epididymitis</td>
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<td>- Stricture</td>
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<tr>
<td>HIV</td>
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<tr>
<td>Maternal conditions</td>
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<tr>
<td>- Maternal haemorrhage</td>
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<tr>
<td>- Sheehan syndrome</td>
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<tr>
<td>- Severe anaemia</td>
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<tr>
<td>- Infertility</td>
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<tr>
<td>Maternal sepsis</td>
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<tr>
<td>- Neurological sequelae</td>
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<tr>
<td>Hypertensive disorders</td>
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<tr>
<td>- Stress incontinence</td>
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<tr>
<td>Obstructed labour</td>
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<tr>
<td>- Recto vaginal fistula</td>
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<tr>
<td>- Infertility</td>
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<tr>
<td>Abortion</td>
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<tr>
<td>Reproductive cancers</td>
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<tr>
<td>- Breast cancer</td>
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<tr>
<td>- Cervical cancer</td>
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<tr>
<td>- Uterine cancer</td>
<td></td>
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<tr>
<td>- Ovarian cancer</td>
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<tr>
<td>- Prostate cancer</td>
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A suggestion put forward was to include a ‘catch all’ category for indirect complications although for consistency, all disease groups would need to reexamine what is not included and should be included. Nonetheless, disease classification rules as defined in the ICD stipulate that maternal conditions should always take precedence over non-maternal diseases and conditions.

Another issue raised relates to less severe complications that have implications over the longer term, for example fistulae. How can these be included, and more generally how can the life span effect be incorporated into the DALYs approach? The consultation recommended that these concerns be considered in the GBD 2000 exercise.

Other aspects of reproductive health not included are gynaecological morbidities including: other STDs (Herpes, HPV); reproductive tract infections such as bacterial vaginosis and trichomonas; menstrual disorders; FGM and other harmful practices and violence related to sexuality and reproduction. Contraceptive morbidity, including the side effects which result from efforts to limit fertility, and psychological morbidity, for example puerperal psychosis, were also identified as important aspects of reproductive ill health that were omitted. A particularly interesting case for further study is the non-availability of contraception; here one is on the fine dividing line between health services and a health state.

It was recommended that existing datasets, for example, containing data on the incidence of obstetric complications, and longitudinal studies on the longer term impact of women’s reproductive conditions be used to gain a greater understanding of reproductive morbidities. An innovative approach based on the concept of obstetric “near miss” (life threatening) complications was also suggested as a possible means of collecting this information.

The DALY calculations do not permit the attribution of healthy years of life until the moment of birth. Stillbirths are therefore not counted as adverse outcomes either for perinatal conditions or for the mother, unless the still birth is associated with a maternal condition such as obstructed labour. It was suggested that this issue might be addressed by valuing the loss from the parents’ perspectives.

Other areas highlighted include: morbidities attributable to HIV and the inter-linkages between HIV and STDs. It was suggested that infertility be treated as a condition in its own right, and not simply as a sequelae of other conditions.

Table 4 summarises the previously neglected aspects of reproductive ill health, identified at the consultation, to be considered in the GBD 2000 study. However, given the limited availability of resources, it was suggested that efforts should focus on the most serious/ highly prevalent diseases.

3.6 Recommendations

A fundamental precursor to better capturing the burden of reproductive health in the GBD 2000 is through improving the epidemiological database.

Participants recognised that much has changed in the recent past; monitoring and surveillance systems have improved in scope and coverage and community based research has broadened
our knowledge base. It was, therefore, recommended that procedures for a more systematic identification, evaluation and use of existing data sources, should be actively promoted in order to make better use of what is already known. A next step needs to be the development of a mechanism that systematically identifies and evaluates sources, maybe by means of an expert panel and through improved linkages between research.

Table 4: Areas of reproductive ill health neglected in the GBD study, 1990

<table>
<thead>
<tr>
<th>Indirect obstetric conditions including:</th>
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<tr>
<td>Malaria</td>
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<td>Anaemia</td>
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<td>Hepatitis</td>
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<td>Diabetes</td>
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<tr>
<td>Epilepsy</td>
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<tr>
<td>Cardiovascular disease</td>
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<tr>
<td>Gynaecologic morbidity including:</td>
</tr>
<tr>
<td>Other STDs (Herpes, HPV)</td>
</tr>
<tr>
<td>Other RTIs (bacterial vaginosis, trichomonas)</td>
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<tr>
<td>FGM and harmful practices</td>
</tr>
<tr>
<td>Violence related to sexuality and reproduction</td>
</tr>
<tr>
<td>Contraceptive morbidity including:</td>
</tr>
<tr>
<td>side effects of contraception</td>
</tr>
<tr>
<td>Psychological morbidity including:</td>
</tr>
<tr>
<td>Puerperal psychosis</td>
</tr>
<tr>
<td>Infertility (not simply as a sequela)</td>
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<tr>
<td>Morbidities attributable to HIV</td>
</tr>
<tr>
<td>Interlinkages HIV/STDs</td>
</tr>
<tr>
<td>Stillbirths</td>
</tr>
</tbody>
</table>

Useful sources of information highlighted by participants included: population surveillance projects, for example Matlab in Bangladesh, Niagkhar in Senegal, Agincourt in South Africa and Novrongo in Ghana; the INDEPTH network in sub-Saharan Africa; historical datasets and European longitudinal studies.

Participants acknowledged that there is still a long way to go in terms of improving the basic data, but that additional funding for large scale epidemiological surveys is unlikely to become available. Therefore, while a broader range of reproductive health conditions should be considered, participants suggested that efforts should be focused on the most serious/highly prevalent conditions. Previously neglected aspects of reproductive ill health to be considered in the GBD 2000 study (see Table 4) were identified. It was suggested that expert panels be convened to assess the probable prevalence (with min/max ranges) of these, particularly where data is weak or lacking. Specific proposals on the collection of this information are covered in the previous section.

The publication and dissemination of age and sex specific results in all cases was also encouraged.
4. VALUING HEALTH STATES

One of the main objectives of this consultation was to evaluate the disability weights, in response to calls for improving the decision-making process of assigning values to different health states.

Assigning values to health states involves four steps:
1. Identifying the population of judges who will assign preferences
2. Sampling and describing the health states from the classification system in order to assign preference weights
3. Selecting a preference measurement method, and
4. Collecting preference judgements, and assigning preference weights to health states.

Three key concerns were raised at the consultation relating to this process.

4.1 Major concerns raised

The first relates to the initial step; that is whose perspective should be reflected in the preference weights? Of particular concern was the validity of using standard disability weights developed through ‘expert’ consensus.

Studies have shown that different responses are given by different types of respondents: the general public, health care providers, individuals living in particular health states or these individuals’ family members (Nord 1992). The general pattern is that health care providers tend to rate health states worse than the general public, who in turn rate them worse than those living in the particular health state. Yet in the GBD study, twelve health professionals (60% male/40% female) from around the world, were asked to evaluate the disability for ‘the average individual with the condition described taking into account the average social response or milieu’ using the person trade-off methodology. Individuals were asked to choose between curing a certain number of individuals in one health state versus another number in a different health state. The methodology elicits the point at which the individual is indifferent between the two choices being offered. At this point the outcomes are equivalent and a weight is derived (Murray 1994). Proponents of the DALY have argued that the person trade off methodology that underlies the DALY weights ensured the methodology could be applied in a consistent manner. However, it can only be used by people with a relatively high degree of literacy and acceptance of trade-off of lives. It is therefore by definition, an exclusive process driven by academic rather than experiential knowledge.

Participants expressed concern at the explicit disavowal by the DALY methodology of community valuation and preferences, which makes no allowance for any differences in disability severity related to social, cultural or economic contexts. This is likely to affect the relevance and acceptability of the weights for particular countries or population groups. Nevertheless, a study presented to the consultation by Ritu Sadana showed how non-health professionals, in a resource poor setting were able to draw reasoned conclusions and rank different disabilities and conditions in a rational and logical fashion using simpler approaches (see section 4.2).

A third issue relates to the lack of transparency of the process whereby disability weights were apportioned among different conditions. The protocol used in the GBD study is described in, Murray and Lopez (1996), The Global Burden of Disease Volume 1, Chapter
Appendix 1. However, this protocol only describes the process used to elicit preference weights for 22 of the indicator conditions. For the remaining conditions and sequelae it appears a very crude approach was used. The protocol states that ‘magnitude estimation and group consensus were used to estimate their distribution across the seven classes of disability using the (22) conditions allocated to each class as pegs on the scale from perfect health to near death’.

4.2 Micro-study on the valuation of health states in a resource poor setting

One challenge facing health sectors particularly in resource poor settings is to integrate the perspectives of marginalized consumers and communities within the policy making and priority setting process. A micro-study in Cambodia within a broader aim of quantifying the burden of illness and disease based on local perceptions, set out to test empirically different approaches to measure the preferences for a wide range of health states and to document the priorities for health sector reform from the point of view of the consumers of health services. Semi-literate and illiterate women of reproductive age (n=40) were sampled from poor communities and from those attending bio-medical and psycho-social reproductive health services in Phnom Penh.

The first stage investigated how women in Cambodia conceptualize the burden of illness and disease, through in-depth interviews, group discussions and key informant interviews. Preliminary results found that when asked about the most common health problems and their negative consequences, women in the community were most likely to discuss reproductive conditions and illnesses. Also women considered ‘health’ to encompass not just illness or disease, but a continuum of positive and negative reproductive conditions, events, morbidities and their consequences. The local conceptual framework of the burden of illness and disease also included: general factors that increase or mitigate the impact of illness or disease – positive or negative outcomes including pain, disability, and social or economic consequences; the social context of reproductive health - personal attributes, status and illness history, household circumstances and institutional and health system factors, as well as indigenously named burdens, social norms and rituals, family or life cycle phase and historical changes in social and political life.

The second stage selected health states and developed culturally appropriate health state descriptions. Next, ranking combined with visual analogue scales, person-trade off and standard gamble methods were attempted to elicit values on hypothetical health states and the women’s current health state. Given the level of abstraction required to use valuation methods, it is not surprising that no one completed a standard gamble valuation. And most individuals were reluctant to conduct any variant of the person trade off approach. All women completed ranking and visual analogue scale (VAS) valuations.

In examining whether contextual factors (seeking care or not, type and severity of illness, age, educational status) affected the values given, only school years appeared to have any impact; states with stigma or shame appeared to show the largest differences in burden for a given level of education. When asked to make a valuation based on their own health state, severity of illness and educational status had some impact, namely women with mild problems and higher levels of education valued health states lower.
In comparing health state values between the GBD study and the Cambodian study it is not surprising that these very different methodological approaches and contexts gave different values. Generally the health states were valued as more severe by the Cambodian women, in particular infertility and vitiligo on the face, yet uni polar depression was judged to be less severe. Also some health states in the Cambodian study were valued as worse than death itself, namely HIV and active psychosis.

An important conclusion that emerged was that improving the validity and reliability of values obtained should certainly not be pursued at the expense of suppressing conflict and different perspectives. This example, using reproductive illness, provided some insight on the different perspectives of the burden of illness and its (dis)value within a specific context.

In documenting the priorities for health sector reform, from the point of view of potential and current consumers of health services, these same Cambodian women more often opted to improve equity over equality and to enhance quality over reduced costs.

The inclusion of community/population values in the social allocation of resources and health policy priorities is a necessary procedure for open debate and social acceptance and may be as important as the technical debates on specific approaches to measurement. Thus, acceptable and feasible methodologies that measure population based values, need to be further tested, that do not impose but reflect social values in a meaningful way, particularly for resource poor areas and marginalized sub-populations often excluded in health policy formulation.

Proponents of the DALY at the consultation, expressed reservations that these results confirmed the basic problem encountered with VAS, namely that people tend to give high weights to mild conditions and that responses do not relate to how resources should be prioritised and spent (Murray an Lopez 1996). On the one hand, arriving at disability weights requires a deliberative process for which a trade off exercise is needed. On the other hand, it was agreed that the process provided some lessons as to how DALY disability weighting exercises could be made more inclusive and representative of a broad range of individuals and perspectives, including socio-economic status, geographic region, gender and disability status.

4.3 Recommendations

While participants recognised that the basic epidemiological data that are used to calculate prevalence and incidence are the most critical inputs to the approach and the most readily improved, they recommended that a more transparent and inclusive process be used to develop disability weights, particularly in the event of applying the DALY approach at local level.

For the GBD 2000 exercise it was recommended that this process should be representative of a more inclusive mix of people, and not only international health experts. These should include those suffering from a condition, their family members, carers and health care providers, the general public and medical practitioners. It was suggested that the WHO Gender Advisory Panel (GAP) be asked to conduct a valuation exercise, next to the groups of experts traditionally used to do so. Also the vignettes used in the valuation exercises, that provide short descriptions of the health condition and its effects, should be improved. They should include a better description of the actual impact of the impairment on daily life.
activities based on results from people in the health state, and should differentiate the socio-cultural, economic and gender specific consequences.

This information should be gathered through a multi country measurement exercise in a range of domains, using a larger array of conditions, to gauge differences in disability severity related to social, cultural or economic contexts. For resource poor areas and marginalized sub-populations this will require acceptable and feasible methodologies that measure population based values and that do not impose but reflect social values in a meaningful way. These need to be further developed and tested.

Finally, any valuation exercise should take place closer to the levels at which the DALY methodology is to be used. If, for example, the use of the DALY is primarily to generate global level assessments of the overall burden of disease, then the use of a panel of experts representative of different regions and specialisations is acceptable. If, on the other hand, the DALY is to be used at the more local level for setting national and sub-national public health priorities, the panels need to be more participatory and inclusive of local communities.
5. CAPTURING THE GENDER DIMENSION IN THE GBD

Are there serious gender biases in the development and application of DALYs in the GBD approach? This consultation provided an important opportunity to raise some critical entry points into this debate. Some concerns were raised regarding the lack of gender focus and resulting bias of the approach, and factors thought to contribute to this bias were highlighted.

Discussion on the gender dimension focused on three essential elements of the DALY framework namely:

- the development of the DALY concept itself and the different choices and assumptions that form the basic framework;
- the availability of gender disaggregated core background data; and
- the problems arising from the application of DALYs in priority setting and resource allocation.

While it was pointed out, in a presentation by Johanne Sundby, that gender and women’s issues are not synonymous, discussion concentrated on the burden of disease of women and whether DALYs adequately captured this (in relation to that of men).

5.1 Gender differences in health

In addressing this issue of the disease burden of women (in relation to that of men), three elements are worth remembering:

- some diseases affect women only and not men and some only affect men, not women;
- some diseases affect women differently from men; and
- some diseases have more severe consequences for women than for men.

It is argued in many settings that men ‘die sooner’ while women ‘suffer more’. That is, while women have a higher life expectancy, they also have a higher share of the disease burden. This may be due to longevity alone, but also to the fact that women suffer more from chronic diseases that are not life threatening. The factors contributing to these differences are varied. Some are linked to gender-specific biological or reproductive factors, others to women’s social and economic status, their differential access to diagnostic tools, differences in care seeking behaviour, coping with and exposure to illness.

Weaknesses of the DALY methodology in capturing these gender inequities and the consequent differences in health risk, disease frequency and disease burden, were highlighted at the consultation and are outlined below.

5.2 Gender bias in the DALY methodology

- Gender roles and identities are not considered

While DALYs measure the impact of impairment on performance, gender roles and identities are not considered. For example, only the inability to take care of oneself in daily activities is measured in the DALY, not the inability to care for others. Women tend to be health caretakers for themselves and their family through low impact interventions in food, hygiene and caring as well as solving and treating minor ailments. Impairment measurements also do
not include the differential impact of the same conditions on women and men. For example, a skin disease can leave women without the chance of getting married, or an infertile woman may find herself divorced against her will. Additionally, no consideration is given to the gender differences in access to resources to alleviate the burden of the condition. Thus, the need for a broadened approach is especially true for the health of women, where social roles account for a lot of the variation in disease and disease tolerance.

- **Using standard life expectancies may understate the disease burden of women**
  Some participants argued that it is not appropriate to use an artificially constructed life expectancy for males as opposed to a real one for women. Using an ‘ideal’ difference in life expectancy of 2.5 years (based on biological differences alone), the DALY methodology may underestimate the disease burden of women relative to that of men. This ‘ideal’ gap is considerably smaller than the observed gender gap in low mortality populations, for example Japan’s is 6 years, factoring out the effects on life expectancy of males’ greater exposure to social and other risk factors. This may have important implications for the estimation of the disease burden of women compared to that of men. The smaller the gender gap, the smaller will be the female contribution to the burden of disease relative to the male contribution. Thus, if the true biological gap is greater than 2.5 years, then the GBD will understate the disease burden of females.

- **Preferences for health states or disability weights may be different for men and women**
  Participants believed that an assessment of preferences may be different for men and women. One difference may be that men value ‘function’ (a masculine ability to be able to act) while women tend to put emphasis also on appearance (a feminine ability to look good). The ranking of diseases affecting the skin or the shape of the body could become very different from this perspective. Thus, women’s values must be adequately represented in this process. It was suggested that the WHO Gender Advisory Panel (GAP) be asked to conduct a valuation exercise, next to the groups of experts traditionally used to do so.

- **Discounting may introduce gender bias**
  The DALY concept has had to balance a relative trade off between preventive care interventions with late benefits compared to interventions that will lead to better health today. This choice may be gender biased since women tend to invest a lot into their own and their children’s health day by day through an emphasis on nutrition, general hygiene and growth monitoring, with a very long time perspective.

- **Lack of gender disaggregated core background data**
  Since the magnitude and outcomes of diseases lack a thorough documentation in many parts of the world, there is a danger that only health issues that are well documented will be reviewed precisely. Women’s advocates have always pointed out that more health data is processed for men than for women, or that when there are no gender disaggregations, the norm is often the adult man. Through looking into the issue of ill health from a gender perspective it becomes clear that not only are women often suffering from conditions that remain undiagnosed (such as asymptomatic STDs), but the consequences of disease in women may be quite different compared with men. Thus the new initiatives to document gender bias may not have been included in the analysis of the DALY methodology. Also the choice of using incidence rather than prevalence data, favours distinct rather than diffuse diseases. Incidence data for diffuse, slowly progressing and chronic diseases or conditions are very difficult to collect and keep. This applies to chronic recurrent diseases as well - issues like menstrual pain effect many women every month, but data on menstrual pain prevalence would never reach any statistical yearbook.
• **Gender bias may distort the resource allocation debate**

DALYs only measure social differences in the burden of health at a very global (large geographical or socioeconomic subregion) level. In the very difficult discussion around resource allocation, one of the implicit agreed upon statements has always been that limited public resources should always be directed to those in greatest need. The DALY is *per se* not a good tool for estimating the differential burden for a given condition, that are carried by the poor. Indicators world wide may suggest that there is a greater gap between poor and rich across nations and in countries, and that there is an increasing feminisation of poverty or growing inequality. Thus, the exercise of estimating the burden of disease using the DALY framework may distort this resource allocation debate.

Participants generally felt that DALYs are too focused on the biological and genetic differences between men and women and are not increasing our understanding of gender inequities and their impact on health outcomes. The following recommendations were put forward by the group to address these issues.

### 5.3 Recommendations

Participants recommended that the weaknesses outlined above be more widely debated in order to effectively use the DALY and GBD framework in the field. They also suggested:

- the need for a broader approach, based on knowledge of a broader set of gender differences than those that can be attributed to biology alone;
- that information collected be made more useful by encouraging sex disaggregation in all cases; and
- that women’s values be adequately accounted for in the assessment of disability weights or preferences for health states, and that the WHO Gender Advisory Panel (GAP) be asked to conduct a valuation exercise, next to the groups of experts traditionally used.
6. CONCLUSIONS AND RECOMMENDATIONS

This informal consultation on DALYs and Reproductive Health was an important first step towards setting out clear recommendations for improving the DALYs exercise to better capture the full dimensions and complexity of reproductive health conditions in the GBD 2000 exercise.

Four years on from the International Conference on Population and Development in 1994, there is now greater clarity and understanding of the concept of reproductive health, and a recognition of the challenges it poses from a measurement perspective. This is because it cuts across the lines along which diseases have traditionally been classified. But also in reproductive health people’s own perceptions of health and disease and the value they put on different health states may differ from what the clinician diagnoses or the epidemiologist investigates. Thus good sexual and reproductive health is manifestly far more than just the absence of disease.

Given the measurement tools available it is inevitable that we must fall back on measures of mortality, morbidity and disability. The DALY methodology permits us, for the first time, to count not only the deaths but also the immense burden of suffering among those who do not die. A first important step has been taken but we must take up the challenge of doing better next time.

This consultation identified several means by which this might be achieved. These are described in detail in the recommendations contained in the body of this report and are summarised below.

It was recommended that:

An electronic network (eg. LISTSERVE) be set up to facilitate continued discussion on the key issues highlighted at the consultation.

A list of conditions, causes, behaviours and risk factors that adequately reflect the burden of reproductive ill health should be established.

It was recommended that a broader range of reproductive health conditions be considered in the GBD 2000 exercise. A first step has been taken in identifying previously neglected aspects of reproductive ill health (see Table 4). Next an expert panel should make a more thorough assessment of what should be included, taking the suggestions in Table 4 as a basis. Given the limited resources available, it was suggested that efforts should be focussed on the most serious/highly prevalent diseases.

The underlying epidemiological data must be improved.

This could be achieved through:

- Improving the use of existing data sources through improved linkages between research groups, and the development of a mechanism that systematically identifies and evaluates sources, possibly by means of an expert panel. The consultation identified a number of useful sources of information on the epidemiology of specific conditions that were not utilised in the 1990 GBD study (see section 3.6 Recommendations for improving the epidemiological database).
• Introducing better data collection methods through continued research on the application and adaptation of promising methods for epidemiological surveillance in poorer populations must be encouraged, including alternatives to complete vital registration such as 'verbal autopsies', and applied research on the cost-effectiveness of different systems for data collection.

• Finding better ways of measuring deaths and disabilities, such as better instruments for measuring the incidence and/or prevalence of important reproductive conditions, valid and reliable instruments for measuring disability at the individual level, and cohort studies on the medium and long term disabling sequelae are urgently required.

• Encouraging the publication of age and sex disaggregated information in all cases.

• Providing best estimates where data are weak or lacking by setting up an expert panel to assess the probable prevalence of conditions, including min/max ranges.

Methods for valuing health states must be improved.
A number of steps were recommended for this purpose:

• Make the process more transparent and representative by bringing together a more inclusive mix of people, not just international health experts. It was suggested that the WHO Gender Advisory Panel (GAP) be asked to conduct a valuation exercise.

• Improve the vignettes to include a better description of the actual impact of impairment on daily life activities based on results from people actually in the health state, and to differentiate socio-cultural, economic and gender specific consequences. A multi country measurement exercise has been planned in a range of domains, using a larger array of conditions, to gauge differences in disability severity related to social, cultural or economic contexts.

• Develop methodologies that measure population based values in resource poor areas and marginalized sub-populations.

• Ensure that valuation exercises take place closer to the levels at which the DALY methodology is to be used.

At the consultation it was also stressed that DALYs must be seen as only one of a set of information requirements necessary for the rational evaluation of policies for health improvement at national level. The involvement of all stakeholders and of local communities, including marginalised groups, is a prerequisite for the rational and fair allocation of resources and for priority setting in resource constrained settings.
7. REFERENCES


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Annex 1: Classification of Reproductive Mortality and Morbidity

Obstetric mortality and morbidity

Direct obstetric mortality and morbidity: results from obstetric complications of the pregnant states (pregnancy, labour and the puerperium), from interventions, omissions, incorrect treatment, or from a chain of events resulting from any of the above. Morbidity can include temporary, mild or severe conditions which occur during pregnancy and within 42 days of delivery (such as haemorrhage, eclampsia or sepsis) or permanent/chronic conditions that persist beyond the puerperium (such as obstetric fistula, urinary or faecal incontinence, scarred uterus, pelvic inflammatory disease, palsy, Sheehan's syndrome). Some chronic conditions such as hypertension can be caused by or aggravated by pregnancy and delivery but may have other causes too.

Indirect obstetric mortality and morbidity: results from existing disease which is aggravated by the physiologic effects of pregnancy (such as anaemia, malaria, hepatitis, tuberculosis, cardiovascular disease). Indirect obstetric morbidity may occur at any time and continue beyond the reproductive period. To the extent that breast cancer progresses more rapidly during pregnancy, it should also be included here.

Nonobstetric mortality and morbidity: in the past mortality and morbidity arising from "fortuitous" or "accidental" causes was not included under pregnancy-related causes of death or disability. More recently, because of the difficulty in distinguishing between conditions that are exacerbated by pregnancy and those which are not and determining whether external causes (suicide, violence) are pregnancy-related, it is proposed that this category be included under maternal mortality and morbidity.

Psychological obstetric morbidity: this may include puerperal psychoses, postpartum depression (baby blues), suicide or strong fear of pregnancy and childbirth that may be the result of obstetric complications, interventions or cultural practices.

Gynaecological mortality and morbidity

Includes reproductive tract infections (RTIs) whether endogenous, exogenous or iatrogenic, and their sequelae (cervical cancer, pelvic inflammatory disease, infertility, HIV/AIDS); cancers of the cervix, breast, endometrium, ovary, vagina, vulva and fallopian tube; endocrinial disorders; menstrual disorders; infertility; congenital malformations; coital injuries (such as following rape or sexual abuse); injuries caused by harmful practices such as female genital mutilation; sexual dysfunction; psychological disorders (such as those associated with sexually transmitted diseases, infertility, traditional practices such as female genital mutilation or Gishiri cuts, dyspareunia, fistulae); menopausal symptoms.

Contraceptive mortality and morbidity

Includes conditions which result from efforts (other than abortion) to limit fertility, whether they are traditional or modern methods. Contraceptive morbidities are of two broad types: local effects of contraceptives such as irritation or allergic reactions to barrier contraceptives, IUD-associated bleeding, or infection of wound sites (implants, tubal sterilization); and systemic effects such as impact on the cardiovascular and hormonal systems and carcinogenicity.

Annex 2: List of Participants

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Annex 3 : Agenda

DALYs and Reproductive Health - A Critical Evaluation
27-28 April 1998

Monday, 27 April 1998

9.00-9.30 Welcome and introduction of participants
   Rationale and objectives
   - background
   - objectives

9.30-10.30 The DALYs approach to measuring the burden of reproductive ill-health
   - how the estimates were derived
   - the formulas and calculations used
   - the reasoning behind these

10.30-11.00 Coffee Break

11.00-12.30 Discussion on DALYs approach

12.30-14.00 Lunch

14.00-15.30 Available evidence on the incidence and prevalence of reproductive ill health
   - Do we know more now?
   more conditions covered, better information on the incidence and prevalence of complications
   - How can this be best used to improve on existing estimates?

15.30-16.00 Coffee Break

16.00-17.30 Discussion on research needs on the epidemiology of reproductive health
   formulation of research agenda

Tuesday, 28 April 1998

9.00-10.00 Assessing the disability weightings used for reproductive health
   The decision-making process of assigning values to different health states

10.00-10.30 Different perspectives of reproductive health disability
   - Do different groups of people make different judgements?

and

11.00-11.30 - What are the implications of these differences?
   - How can the process be made more inclusive and representative of a wide range of individuals and perspectives?
Tuesday, 28 April 1998

10.30-11.00 Coffee Break

11.30-12.30 Discussion on further research needs relating to the disability weightings

12.30-13.30 Lunch

13.30-14.00 Incorporating the gender perspective into the DALYs methodology

14.00-14.30 Discussion on the gender perspective

14.30-15.00 The challenge of using DALYs for allocating resources at different levels
- Ideas and approaches for applying DALYs in different settings

15.00-15.30 Discussion on ideas and approaches for applying DALYs in different settings

15.30-16.00 Coffee Break

16.00-16.30 Discussion continued

16.30-17.30 Conclusions and recommendation
- Further research
- Next steps