

**Information Needs for Research, Policy and Action on Ageing and Older Adults**

**Report on a WHO Workshop:  
Minimum Data Set Version 1.0 on Ageing and  
Adult Mortality Data in sub-Saharan Africa**

Pretoria, South Africa  
12 - 14 February 2003

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**Evidence and Information for Policy  
World Health Organization**



**U.S. National Institute on Aging**

**HelpAge  
International**

*Leading global action on ageing*

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Thirty-three persons participated in the workshop, and their contribution both prior to and during the workshop is gratefully acknowledged. A list of the participants is given in Appendix 1. Professor Monica Ferreira also contributed to the preparation of this Workshop Report.

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### **Note:**

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**List of Terms**

AFRO	WHO Regional Office for Africa
AMMP	Tanzania Adult Morbidity and Mortality Project
AU	African Union
BoD	Burden of Disease study
CSO	Central Statistics Office
CWIQ	Core Welfare Indicators Questionnaire
DHS	Demographic and Health Survey
DSS	Demographic Surveillance Site
FAO	Food and Agriculture Organization of the United Nations
GBD	Global Burden of Disease
GLSS	Ghana Living Standards Survey
HAI	HelpAge International
HALE	Healthy life expectancy
HBS	Household Budget Survey
HSRC	Human Sciences Research Council
IAG	International Association of Gerontology
ICDS	Inter-Census Demographic Survey
ICPSR	Inter-university Consortium for Political and Social Research
ICES	Income, Consumption and Expenditure Survey
INDEPTH	An International Network of fieldsites with continuous Demographic Evaluation of Populations and Their Health in developing countries
MCSS	WHO Multi-Country Survey Study
MDG	Millennium Development Goals
MDS	Minimum Data Set
MoH	Ministry of Health
NEPAD	New Partnership for Africa's Development
MRC	Medical Research Council
NGO	Non-governmental organization
LFS	Labour Force Survey
NBD	National Burden of Disease
NIA	United States National Institute on Aging
OAU	Organization for African Unity
OHS	October Household Survey
PRSP	Poverty Reduction Strategy Papers
SRS	Sample Registration System
TSED	Tanzania Social and Economic Database
UN	United Nations
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNDP	United Nations Development Programme
UNFPA	United Nations Population Fund
WB	World Bank
WHO	World Health Organization
WHS	World Health Survey

## **Executive Summary**

The WHO workshop on the Minimum Data Set (MDS) on Ageing Version 1.0 and Adult Mortality Data in sub-Saharan Africa was held in Pretoria, South Africa from 12 to 14 February 2003. Previous workshops were held in Harare, Zimbabwe (January 2000) and Dar es Salaam, United Republic of Tanzania (June 2001). This workshop was held to improve the understanding of the processes and challenges to collate available data in each country, to finalize the first phase of the MDS Project, and to identify data gaps and strategies to address those gaps. The workshop particularly focused on key gaps in basic health status information, with particular reference to the comparable measurement of health status and of older adult mortality rates.

The four MDS Project country work groups (Ghana, South Africa, United Republic of Tanzania and Zimbabwe) presented work done to create a data set for their country. The compilation of combined data for the four countries to create the MDS Version 1.0 was presented by the Human Sciences Research Council. Data were not available for many of the 44 indicators and where data were available, differences in definitions or measurement issues limited comparability.

The compilation of Version 1.0 of the MDS highlighted the almost total absence of comparable data on the health status of older adults, on their use of health services, and on risks and determinants of mortality. The workshop focused on addressing these gaps, particularly through the implementation of the World Health Survey (WHS) in a large number of African countries and through examination of other strategies to improve information on cause of death statistics in African countries.

The WHS has been created to address two major challenges facing health policy-makers at the national and international levels: 1) the need for comparable and reliable information on population health; and 2) baseline evidence on the way health systems are currently functioning, and/or a strategy to monitor inputs, functions, and outcomes. Seventy-three countries are presently carrying out the survey distributed across the six WHO Regions. Eighteen countries in sub-Saharan Africa are working with WHO in this round of the survey, three of which are including an oversample of respondents aged 50 years and older.

The WHS will provide health and health-related data on older persons and will be used as a platform for longitudinal study of this population. Three countries, Ghana, South Africa and Zimbabwe, will be included in annual longitudinal follow-up for at least two rounds, providing much needed data on changes, trends and patterns in health status. The addition of a longitudinal component to the current plans for the WHS will enable the assessment of health changes over time on an individual basis and direct linkages between non-fatal health experiences and mortality in settings where these types of data are limited. Of particular value will be the collection of longitudinal data on aging populations in developing countries using standardized instruments designed to enhance cross-population comparability.

Available cause of death data were reviewed and data collection systems examined for nine countries in sub-Saharan Africa. Vital registration systems, demographic surveillance sites, population censuses and hospitals as valuable sources of mortality data were discussed specifically. National mortality rates were found to be incomplete for the majority of the countries represented in the workshop. It was noted that many countries have a legislative system in place, and that in some countries there is good coverage of death registration, but no system to collect statistics and a lack of infrastructure to obtain cause of death details. Strategies were proposed to improve the amount and quality of mortality data in the region, with particular emphasis on improvement of vital registration systems and on the development of sample registration systems similar to those in use in demographic surveillance sites that are members of the INDEPTH network, and in India and China.

Five core criteria were discussed for the development of data and evidence to support policy: validity, reliability, cross-population comparability, an explicit audit trail, and consultation with data providers. Such information must be distinguished from data collections and extracted datasets, which need not meet these criteria, but provide valuable inputs to the production of information for policy makers, and are the starting point for the data audit trail. The MDS Project up until recently has focused on the identification and collection of input datasets in collaboration with country teams in four African countries. This process has identified major gaps and deficiencies in existing data sources, considerable barriers to accessing such data, problems with validity and comparability of the data, and resource problems in assembling the input datasets.

Current and future efforts to collaborate with countries in the African region are thus focusing on the development of primary data collection through the World Health Survey (involving an oversample of older persons and a longitudinal component) and on the strengthening of primary data collections to measure adult mortality (vital registration systems, sample registration systems and survey methods). Verbal autopsy tools will play a key role in obtaining basic information on causes of death and there is a great need for studies to improve such instruments.

The continuing development of a minimum or core dataset of indicators, covering important quantities of policy interest, is also a priority. Such an information base should contain a complete matrix of valid and comparable estimates for standard population categories (age, sex, etc.), as well as metadata including reliability information and a data audit trail. The development of such an indicator minimum dataset should be carried out in close collaboration with countries, with the WHO Regional Office, and with other international indicator development, particularly that associated with the Millennium Development Goals and with the proposed Health Metrics Network currently under discussion between WHO and other international bodies.

## 1. Introduction

The WHO workshop on the Minimum Data Set (MDS) on Ageing Version 1.0 and Adult Mortality Data Sources in sub-Saharan Africa was held in Pretoria, South Africa on 12-14 February 2003. Previous workshops were held in Harare, Zimbabwe (January 2000) and Dar es Salaam, Tanzania (June 2001). This third workshop focused on the finalization of the first phase of the MDS Project and provided an opportunity to identify areas and issues to include in future work plans, particularly an increased focus on basic health data needs (with particular reference to the comparable measurements of health status and of older adult mortality rates). Thirty-three persons participated in the workshop, which was held in the Human Sciences Research Council Building. A list of the participants is given in Appendix 1.

The four MDS Project country work groups (Ghana, South Africa, United Republic of Tanzania and Zimbabwe) presented work done to create a data set for their country. The compilation of combined data for the four countries to create the MDS Version 1.0 was presented by the Human Sciences Research Council. Data were not available for many of the 44 indicators and where data were available, differences in definitions or measurement issues limited comparability.

The process for developing indicators for the MDS Version 1.0, including establishing methods and identifying available data for the indicators, is described in earlier MDS Project reports (available online and in hardcopy<sup>a</sup>). Further development and use of the indicators will be carried out in close collaboration with countries, with the WHO regional office, and with other international indicator development, particularly that associated with the Millennium Development Goals and with the proposed Health Metrics Network currently under discussion between WHO and other international bodies.

The compilation of Version 1.0 of the MDS highlighted the almost total absence of comparable data on the health status of older adults, on their use of health services, and on risks and determinants of mortality. The workshop focused on addressing these gaps, particularly through the implementation of the World Health Survey (WHS) in a large number of African countries and through an examination of other strategies to improve information on adult mortality in African countries.

### 1.1 Evidence to inform policy formulation on adult health and ageing in Africa

As identified in presentations at this and previous workshops, access to basic information on older persons has been so constrained in the developing world that there is little expectation or demand for evidence as the basis for decisions. The amount and quality of basic data on older persons remains insufficient for a variety of research, policy and decision-making purposes at the national level, and is particularly problematic at the sub-national level. The lack of evidence to inform national policy formulation may be one of the contributing factors to why many countries have not moved much beyond the signing of the 1982 Vienna

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<sup>a</sup> World Health Organization, WHOSIS, 2003. MDS Project at: <http://www.who.int/whosis/mds>

International Plan of Action on Ageing. International and regional efforts to assist countries with policy formulation and implementation, as listed in Table 1.1, have had mixed results over the past two decades.

**Table 1.1 Important international and regional policy strategies and frameworks**

Year	Policy initiative
1982	Vienna International Plan of Action on Ageing
2000	UN Millennium Development Goals <a href="http://www.developmentgoals.org/">http://www.developmentgoals.org/</a>
2002	Madrid International Plan of Action on Ageing <a href="http://www.un.org/esa/socdev/ageing/ageraa.htm">http://www.un.org/esa/socdev/ageing/ageraa.htm</a>
2002	African Union Policy Framework and Plan of Action on Ageing <a href="http://www.helpage.org/images/pdfs/AUFrameworkBook.pdf">http://www.helpage.org/images/pdfs/AUFrameworkBook.pdf</a>

As Table 1.2 shows, the status of ageing policies varies by country and remains somewhat of a novelty in sub-Saharan Africa. Few countries have a policy, yet encouraging information from HelpAge International indicates that the recent attention from the policy initiatives mentioned previously has prompted many countries to begin the process of developing ageing policies – or at least include older adults in other policies. The challenge continues to be how are policies created when we know that few data are available to inform those policy making processes. High quality data and political support will assist with preparations for an ageing population.

**Table 1.2 Status of ageing policies for selected countries**

Country	National Policy on Ageing (yes, no, pending)	Country	National Policy on Ageing (yes, no, pending)
Benin	No	Mozambique	Yes
Botswana	No	Nigeria	Yes
Burundi	Pending	Rwanda	Pending
Cameroon	Yes	Seychelles	No
Eritrea	No	Sierra Leone	No
Ethiopia	Yes	South Africa	Yes
Ghana	Pending	Sudan	No
Kenya	Pending	Swaziland	No
Lesotho	No	United Republic of Tanzania	Pending
Madagascar	Pending	Uganda	Pending
Malawi	Pending	Zambia	No
Mali	Yes	Zimbabwe	Pending
Mauritius	Yes		

Sources: WHO; HelpAge International, State of the World's Older People 2002.

(<http://www.helpage.org/images/pdfs/SOTWOPeng.pdf>)

## 1.2. Aims and Objectives of the Workshop

1. To finalize MDS Version 1.0 and the first phase of the MDS Project.
2. To review existing data sources and mortality data collection systems, e.g., vital statistics and the World Health Survey.
3. To examine mechanisms towards developing work in a second phase of the project, specifically on the longitudinal study of adult health and ageing.

4. To discuss the role of the World Health Survey and vital registration systems in providing needed health data and practical steps to guide activities at country level.
5. To determine ways to access and improve sources of adult mortality data in African countries.
6. To clarify plans and actions to improve vital registration systems in selected countries.
7. To identify additional strategies to improve health and mortality data including verbal autopsy and validation studies, e.g., through funding and technical assistance.

### **1.3. MDS Project Background**

A brief overview of the MDS project was provided by Paul Kowal. The World Health Organization (WHO) initiated the Minimum Data Set (MDS) Project in 1999 with funding support from the National Institute on Aging (NIA) and set up collaborative activities with work groups in Ghana, South Africa, the United Republic of Tanzania and Zimbabwe, HelpAge International (HAI) and other regional and international groups. A major goal for the project was to create a set of valid, reliable and timely data that described the situation of the older population in sub-Saharan Africa (Kowal, et al. 2002). These data would be consolidated into indicators linked to targets and goals which would inform research, policy and public opinion. The indicators established thusfar have been linked to the UN's Millennium Development Goals,<sup>b</sup> the UN International Plan of Action on Ageing,<sup>c</sup> the African Union's Policy Framework and Plan of Action on Ageing,<sup>d</sup> and the Poverty Reduction Strategy Papers (PRSP)<sup>e</sup> processes.

A major challenge in African countries is thus how to develop policies to benefit older adults when so few data are available to inform policy making processes. High quality data can contribute to relevant, effective and timely planning for an ageing population.

## **2. Health and health-related data**

### **2.1 Evidence for health policy**

In many countries, national capacity and resources – human, financial, and material – are still insufficient to ensure availability of and access to essential health and welfare services of high quality for older individuals and populations, especially those most vulnerable. Problems include the inability of governments to assure quality of providers and of service delivery; fragmented services that lead to inequitable coverage, inefficiencies in resource

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<sup>b</sup> UN Millennium Development Goals 2000.

<sup>c</sup> UN International Plan of Action on Ageing – 2002. “The Madrid Plan specifies that ageing should be mainstreamed into global development and social policy processes (such as poverty reduction strategies and national development plans), and contains detailed sections on growing areas of concern for older people and their families, such as poverty, HIV/AIDS, violence and abuse, access to health services and social protection.”

<sup>d</sup> AU Policy Framework and Plan of Action on Ageing – 2002. Endorsed by the OAU, Labour and Social Affairs Commission in April 2002 and approved at the Heads of States Summit in July 2002.

<sup>e</sup> Development of the health component of the poverty and social impact analysis of major policy reforms – in particular relating to older populations in Africa.

[http://www.afro.who.int/des/events/infonote\\_prsp\\_dakar.pdf](http://www.afro.who.int/des/events/infonote_prsp_dakar.pdf)

allocation and management, and imbalances in human resources. The pressing health and social issues related to other age groups has resulted in further marginalizing older persons.

Better evidence is needed on the relationship between the performance and organization of different health systems for older persons, and on ways to manage the complex process of change. Decision-makers need reliable information on the cost, effectiveness and efficiency of interventions in a timely and useable fashion, targeting the health of the poor, who are often older persons. In addition, information on ethical and gender dimensions of choice of intervention, system design, quality of care, and ways to encourage desirable and discourage undesirable interventions, all feed into the policy debate. In order to meet these challenges, decision-makers need the tools, information and capacity to assess health needs, choose intervention strategies, design policy options appropriate to their own circumstances, monitor performance and manage change.

WHO provided an overview of issues in the collection of health and health-related data for the development of evidence to support health and ageing policy. An outline was presented of the WHO approach to the development of data and evidence to support policy (Murray, Mathers & Salomon 2003).

It is useful to distinguish at least two types of primary audiences for such information. First, WHO publishes information to inform international and national health policy debates. As an international organization, information published by the WHO is frequently used for benchmarking, for advocacy of particular policies, for monitoring achievements towards internationally accepted goals and targets and to guide technical strategies and responses. Second, WHO disseminates data and figures whose primary use is as an input to research studies and analyses. The uses of such information are often hard to predict; for example, making microdata available from surveys can be considered a form of public good.

WHO has developed principles that should govern the collection and dissemination of figures for both types of audiences (see Figure 2.1). These are briefly summarized below:

#### ***Clearly Defined Quantities of Interest***

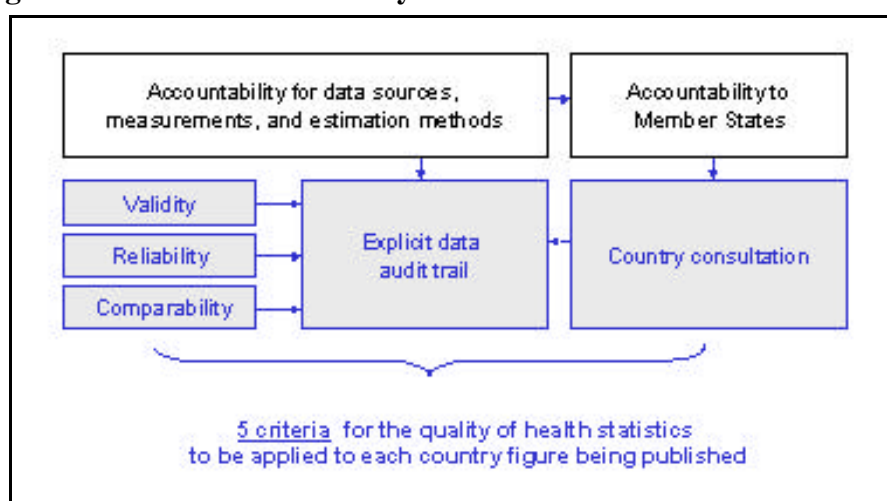
The most important principle is to clearly and unambiguously define the quantity of interest for an indicator. With reference to descriptive epidemiology to inform health policy debates, most often the quantity of interest is the population incidence, prevalence or mortality numbers or rates of a disease, injury, impairment, or risk factor. For example, the quantity of interest reported annually by WHO for each Member State is a set of population age-specific mortality rates. For research audiences, however, WHO also publishes a different quantity of interest, namely, "Deaths detected by the civil registration system". As many civil registration systems detect only a fraction of total deaths, the quantity "Deaths in the population" is distinctly different than "Deaths detected by the civil registration system". It is important to communicate to all users of figures exactly what is the quantity of interest that is being published.

### ***Validity and Reliability***

Validity is the extent to which a figure measures the quantity of interest. The validity of all figures for quantities of interest should be established. All figures are estimates that have some uncertainty interval. The uncertainty interval is a function of sampling error, error due to the measurement instrument, error due to parameter and fundamental uncertainty in models used to correct for known biases or to deal with missing data. Explicit uncertainty intervals should be reported in nearly all cases for all quantities of interest. In cases where the quantity of interest has by definition nearly no uncertainty, reporting intervals may be unnecessary. For example, if the quantity of interest is program expenditure on older people and figures are based on a detailed expenditure statement based on individual service data, the uncertainty interval may simply be the point estimate. On the other hand, if these figures have been estimated using aggregate data and some inferred proportion of services going to older people, then some uncertainty must exist.

Reliability is the extent to which repeated measurement will give the same result. Reliability is a function of instrument measurement error. Instruments with low reliability have large measurement error and vice-versa. If uncertainty intervals are routinely reported the user of information is implicitly provided with information on the reliability of the measurement.

**Figure 2.1 WHO Accountability Framework for Data to Inform Policy**



### ***Comparability***

The very act of compiling information for countries or subnational population groups along side of each other encourages users to make comparisons across groups. In fact, there is no purpose in collecting information which cannot be compared across groups. Likewise publication of the same series for more than one year encourages comparisons overtime. To support this use of information, special efforts should be made to establish the comparability of figures for quantities of interest. As an example, two thermometers

- one in Celsius and the other in Fahrenheit - may both be valid and reliable measures of temperature but the results of the two are not comparable. Establishing cross-population or inter-temporal comparability requires an explicit strategy in the development and operationalization of figures for a quantity of interest.

### ***Data Audit Trail***

In an era when accountability is a key issue for governments and for the international community, WHO should be accountable for the figures it publishes. An explicit and detailed data audit trail should be provided so that any user of published figures can trace the origin of a point estimate and uncertainty interval for a figure. Take a country where the estimate for 5q0 for 2000 is 150. The data audit trail should indicate the survey data, year, sample size, and the model used to update the estimates based on these surveys to the year 2000. The goal of the data audit trail should be complete transparency in the development of figures. The data audit trail should be specific for each figure and not general statements on types of sources and methods. For registry data for publicly managed health or welfare services, the data audit trail should indicate the completeness of facilities covered by the national registry data.

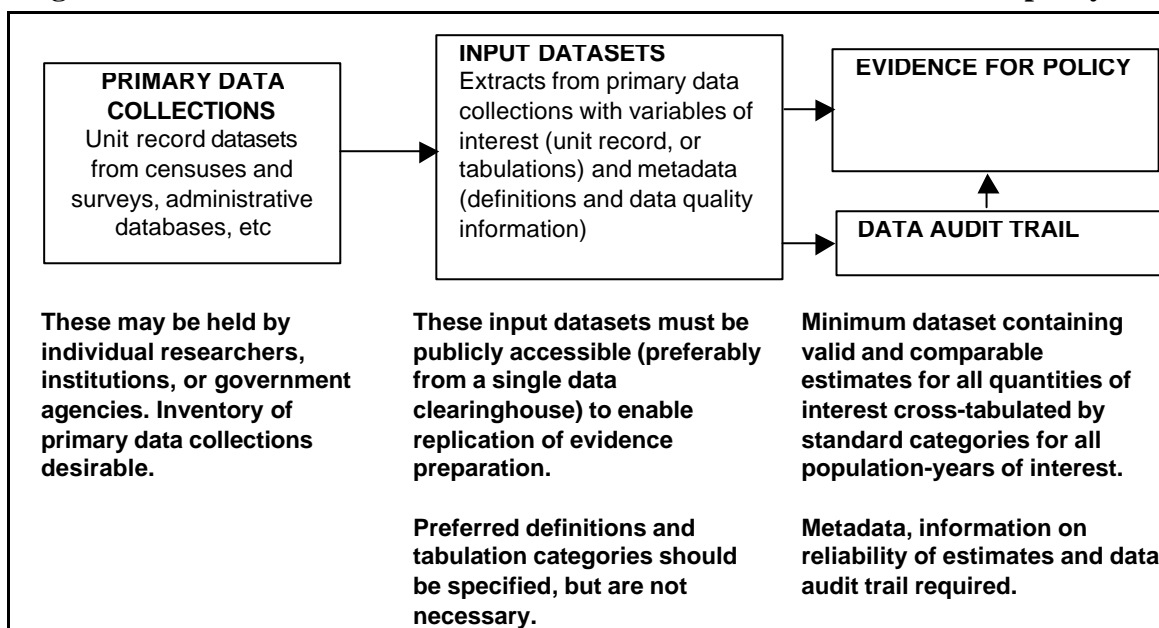
### ***Consultation with data providers***

A cycle of consultation with data providers is important to review the data and enable primary data sources that may not have been previously reported or used to be identified, build mutual understanding of the strengths and weaknesses of available data and ensure broad ownership of the results.

Within the countries present, most issues related to older persons are not a priority. These issues receive little attention when competing with issues related to children, adolescent and maternal health. In addition to cross-national comparability, the consultation process should also consider the value of such data for planning/policy purposes within individual countries.

Information that is intended for use by policy makers and analysts should meet these five core criteria: validity, reliability, cross-population comparability, explicit audit trail, and consultation with data providers. Such information must be distinguished from other data and datasets: these may include information that is not necessarily valid (e.g., it may be incomplete or for a subgroup only) and not necessarily comparable with other data. Such information is useful as input for research and analysis, and provides inputs to the production of validated information for policy.

This distinction is illustrated in Figure 2.2. Primary data collections provide input datasets for analysis. The former may not be publicly available (for example, census unit record data) but the latter should be, as the starting point of the data audit trail. Input datasets do not necessarily need to cover all population categories of interest or use standard definitions for quantities of interest or for analysis categories. Thus, for example, data on risk factor distributions in older people may only be available for certain age categories. These can be mapped to the standard age groups in a minimum dataset using other evidence on age patterns.

**Figure 2.2 The transformation of data and information into evidence for policy**

## 2.2 Global burden of disease in ageing populations

The Global Burden of Disease in Ageing Populations study (also funded by the National Institute on Aging under a separate grant), has focused on the development of population health information at the global and regional level to inform health policy. Precise information about diseases and injuries, their incidences, their consequence, their causation and their trend is more than ever necessary to inform policy-making. In 1993, the Harvard School of Public Health, in collaboration with The World Bank and WHO, assessed the Global Burden of Disease (GBD) (Murray and Lopez 1996). The World Health Organization is now undertaking a new assessment of the GBD for the year 2000 and subsequent years. Colin Mathers provided an overview of the GBD2000 objectives, methods, data sources and results.

The specific objectives of GBD2000 are:

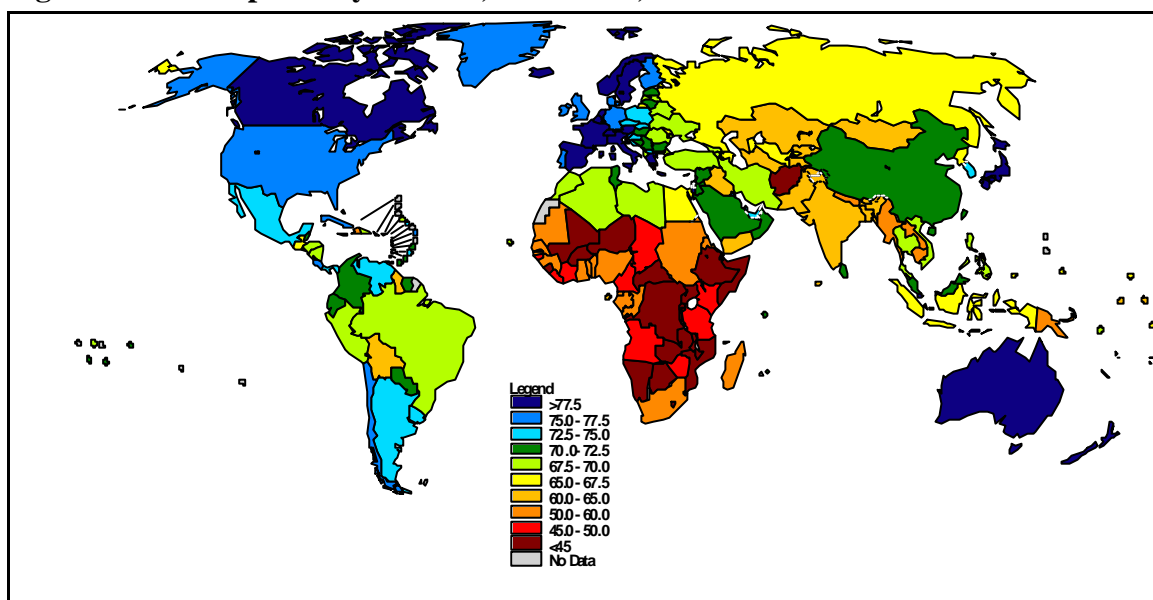
- to quantify the burden of premature mortality and disability by age, sex, and region for 135 major causes or groups of causes, with a particular focus on older populations;
  - to analyze the contribution to this burden of selected risk factors using a comparable framework; and
  - to develop various projection scenarios of the burden of disease over the next 30 years.
- The data sources and methods used in the GBD2000 study are documented by Mathers et al. (2002) and summary results for 14 regions of the world are published in the World Health Report (WHO 2002) and on the world wide web ([www.who.int/evidence/bod](http://www.who.int/evidence/bod)).

Procedures used to estimate mortality rates and construct life tables differ for Member States depending on the data availability to assess child and adult mortality. For Member States without exploitable vital registration data, other sources of child and adult mortality such as

surveys and censuses are used (Mathers et al. 2002). For the 53 countries lacking data on adult mortality, including many African countries, based on the measured or projected level of child mortality in 2000, the most likely corresponding level of adult mortality (excluding HIV/AIDS deaths where necessary) was estimated, along with uncertainty ranges. Adult mortality levels were based on regression models of child versus adult mortality as observed in a set of almost 2000 life tables judged to be of good quality (for figures, see Mathers, et al. 2002).

Figure 2.3 shows variations in life expectancy at birth, for both sexes, across the countries of the world for 2000 (Version 2 estimates). On average, HIV/AIDS has reduced life expectancy at birth for sub-Saharan Africans by six years in 2000. In Zimbabwe, Botswana and Namibia, male and female life expectancies would be around 20 years higher if there were no deaths due to HIV/AIDS.

**Figure 2.3 Life expectancy at birth, both sexes, 2000**



WHO uses data provided by Member States, together with all available other sources of information on causes of death, to estimate death rates by age, sex for underlying causes of death as defined by the International Statistical Classification of Diseases and Related Health Problems (ICD) classification rules. For countries where no vital registration data or sample registration exist, causes of death models are first used to estimate the maximum likelihood distribution across (WHO disease) Groups I, II and III based on estimated total mortality rates and income. In the case of WHO African region where good vital registration data is existent for only three countries, a regional model pattern of specific causes of deaths was based on vital registration data from urban and rural South Africa. This regional model pattern was then further adjusted for individual countries on the basis of epidemiological evidence from registries, verbal autopsy studies, disease surveillance systems, and analyses from WHO technical Programmes, as well as on the results from the cause of death models.

The GBD 2000 revisions draw on a wide range of data sources to develop internally consistent estimates of incidence, prevalence, duration and years lived with disability (YLD), for 135 major causes, for 17 WHO sub-regions of the world. YLD are added to YLL (the years lost due to mortality) to calculate disability adjusted life years (DALYs) by cause, age and sex for the 17 regions. Age groups used in the GBD2000 study have been revised to provide more detail on the burden of disease in older populations: 0-4, 5-14, 15-29, 30-44, 45-59, 60-69, 70-79, 80+ years. The leading causes of death and DALYs in the AFRO region are listed in Table 2.1 for Version 2 estimates of the GBD2000. Table 2.2 shows the leading causes of deaths and DALYs among Africans aged 60 years and over.

**Table 2.1. Leading causes of deaths in the WHO African region, Version 2 estimates for 2000**

	<b>African Region (AFRO)</b>	<b>% total deaths</b>		<b>African Region (AFRO)</b>	<b>% total DALYs</b>
1	HIV/AIDS	19.2%	1	HIV/AIDS	17.8%
2	Lower respiratory infections	9.7%	2	Malaria	10.3%
3	Malaria	9.2%	3	Lower respiratory infections	8.4%
4	Diarrhoeal diseases	6.6%	4	Perinatal conditions	6.3%
5	Perinatal conditions	5.8%	5	Diarrhoeal diseases	6.1%
6	Measles	4.3%	6	Measles	4.6%
7	Ischaemic heart disease	3.1%	7	Tuberculosis	2.4%
8	Tuberculosis	3.0%	8	Whooping cough	1.9%
9	Cerebrovascular disease	2.9%	9	Road traffic accidents	1.8%
10	Road traffic accidents	1.7%	10	Protein-energy malnutrition	1.6%
11	Whooping cough	1.6%	11	War	1.5%
12	Tetanus	1.2%	12	Violence	1.4%
13	War	1.1%	13	Unipolar depressive disorders	1.2%
14	Violence	1.1%	14	Tetanus	1.1%
15	COPD	1.1%	15	Congenital anomalies	1.1%

**Table 2.2. Leading causes of deaths and DALYs in people aged 60 years and over, WHO African region, Version 2 estimates for 2000**

	<b>African Region (AMRO)</b>	<b>% total deaths</b>		<b>African Region (AMRO)</b>	<b>% total DALYs</b>
1	Ischaemic heart disease	13.3	1	Ischaemic heart disease	9.4
2	Cerebrovascular disease	11.9	2	Cerebrovascular disease	8.4
3	Lower respiratory infections	7.8	3	Lower respiratory infections	6.0
4	Chronic obstructive pulmonary disease	5.0	4	Cataracts	3.7
5	Diarrhoeal diseases	4.2	5	Chronic obstructive pulmonary disease	3.6
6	Tuberculosis	2.5	6	Trachoma	3.6
7	Prostate cancer	2.2	7	Diarrhoeal diseases	3.4
8	Cirrhosis of the liver	2.2	8	Tuberculosis	2.4
9	Hypertensive heart disease	2.1	9	Cirrhosis of the liver	2.2
10	Diabetes mellitus	2.0	10	Alzheimer and other dementias*	1.8

### 2.3 National burden of disease analyses

WHO member States are increasingly requesting technical assistance and support to undertake country-level burden of disease measurement (Mathers, et al. 2001). Over 30 countries are in various stages of undertaking these assessments and WHO support to these efforts not only ensures better data for planning but also enables further development and testing of tools to facilitate burden of disease assessments. This iterative process builds a partnership between WHO and Member States, laying the groundwork for tackling the bigger challenge of integrating burden of disease data into country-level policy analysis. In the African region, national burden of disease (NBD) studies have been completed for three countries: Mauritius, Zimbabwe and South Africa. Preliminary studies or planning for national studies are underway in several other African countries, including Mozambique, Uganda and Ghana.

NBD studies have been undertaken primarily by Ministries of Health (planning or epidemiology departments), by Government research or statistical agencies or by universities. Some of them have been financed by international agencies like the World Bank and others with local funding. These studies have proved to be of considerable usefulness in guiding health sector reform and for priority setting in countries.

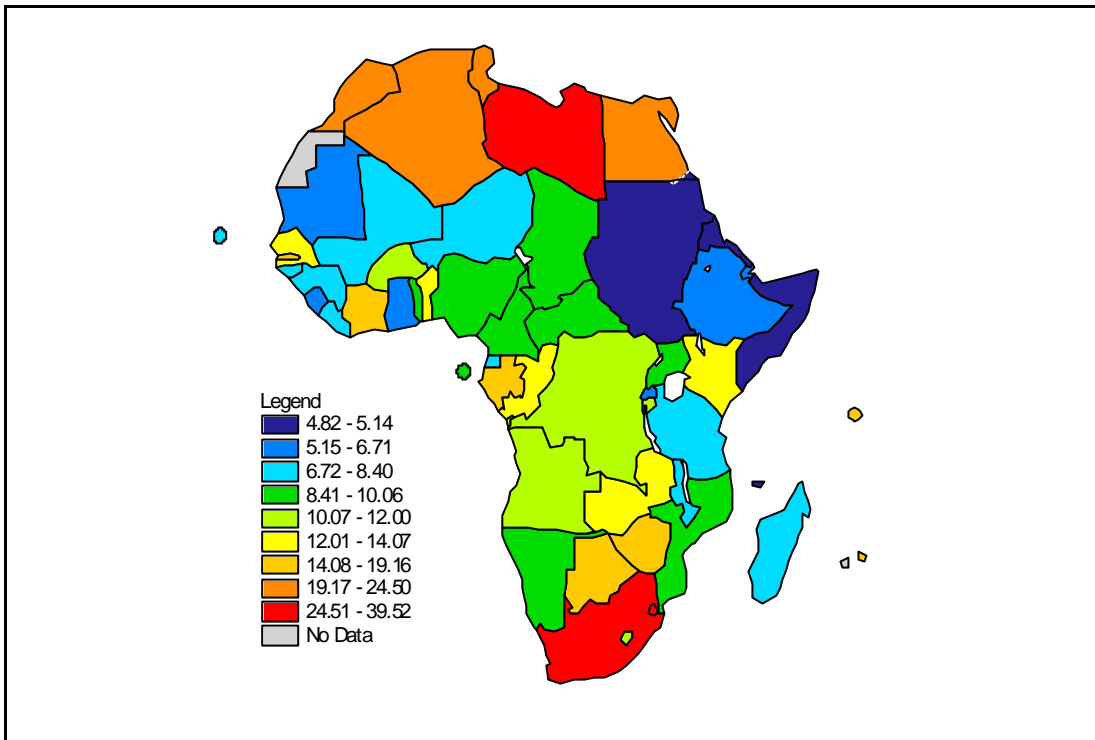
To assist NBD study teams, WHO has developed "prior" estimates of the national burden of disease for all 191 Member States. These prior estimates are based on the regional analyses of the GBD2000 study, together with national estimates for causes of death, and available national-level epidemiological information. These "prior" estimates should be understood as the best available estimates based on the data available to WHO and are intended to provide a starting point for national studies to refine and revise in light of available local information and expert advice.

Figures 2.4 and 2.5 illustrate these prior estimates for African countries for two causes of death. The prior estimates of disease incidence, prevalence and severity by country are also used in the calculation of healthy life expectancy, reported annually in the Annex Tables of the World Health Report. The World Health Report 2003 will include results of the country consultation process on country-level estimates of prevalences for major conditions.

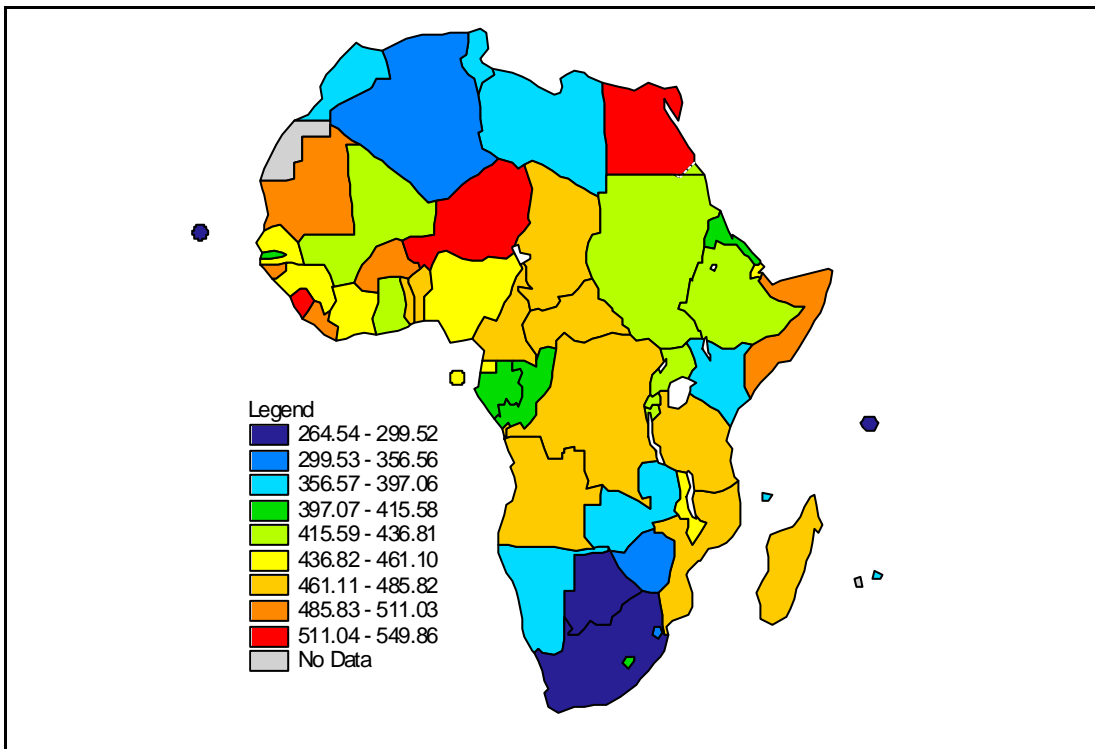
Version 2 of the GBD 2000 also underpins the comparative risk assessments for 25 major risk factors published in the World Health Report 2002 together with analyses of the cost-effectiveness of interventions for these risks which are the main topic of the World Health Report 2002. These comparative risk assessments are now being extended to provide prior estimates for countries of the attributable mortality and burden of disease based on the NBD priors and country-level information on risk factor exposures.

Table 2.3 illustrates the potential outputs of such analyses by showing the top ten risk factors for AFRO D and the ten leading causes of burden of disease from the NBD prior estimates for Nigeria. Figure 2.6 from the World Health Report 2002 summarizes the estimated impact of cost-effective interventions for these risk factors in Africa (WHO region AFRO D) and South America (WHO region AMRO B).

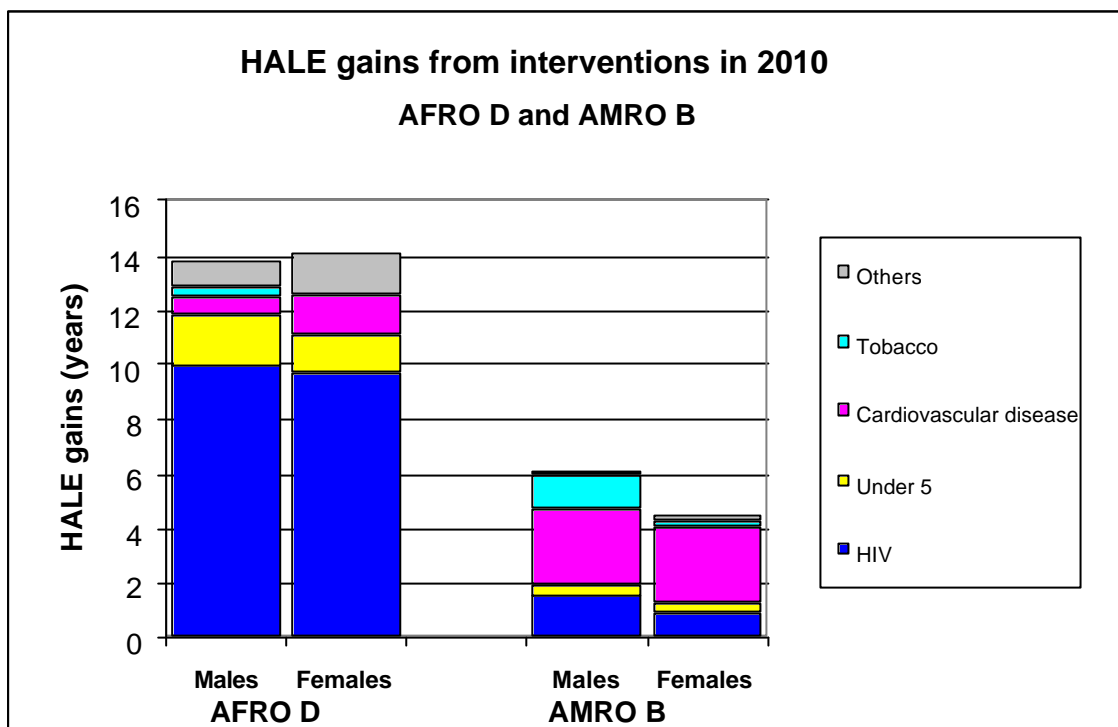
**Figure 2.4 Age-standardized death rate per 100,000 population: Trachea, bronchus and lung cancers, males, 2001**



**Figure 2.5 Age-standardized death rate per 100,000 population: Cardiovascular disease, females, 2001**



**Figure 2.6 Potential gains in healthy life expectancy (HALE) from interventions for selected risk factors.**



Source: World Health Report 2002.

**Table 2.3 Leading 10 selected risk factors (AFRO D) and diseases or injuries (Nigeria prior estimates), 2000**

<b>AFRO D</b>		<b>Nigeria</b>	
<b>Risk factor</b>	<b>% deaths</b>	<b>Disease or injury</b>	<b>% deaths</b>
Underweight	19.2%	Lower respiratory infections	11.5%
Unsafe sex	9.9%	HIV/AIDS	10.4%
Unsafe water, S&H	5.3%	Malaria	9.9%
Blood pressure	4.9%	Measles	6.6%
Vitamin A deficiency	4.6%	Diarrhoeal disease	5.8%
Indoor smoke	4.0%	Perinatal conditions	5.5%
Zinc deficiency	3.3%	Tuberculosis	4.3%
Iron deficiency	2.9%	Ischaemic heart disease	3.7%
Cholesterol	2.0%	Cerebrovascular disease	3.1%
Alcohol	1.6%	Maternal conditions	2.7%

### 3. MDS Version 1.0

The MDS Version 1.0 Indicators were developed using the principles and rationale described in the 2001 Dar es Salaam MDS Meeting Report. The MDS Version 1.0, included 55 core indicators divided into eight categories: A) demographic profile; B) socioeconomic status; C) housing and living arrangements; D) health status, risks and behaviours; E) care; F) social well-being; and G) impact of HIV/AIDS.

The four country work groups had compiled data and metadata for the core indicators, with assistance from the WHO and the HSRC where needed. Data spreadsheets were circulated to the country working groups, and recommendations for format and data submission and transmission provided. Each country submitted data to the WHO and the HSRC, after which the HSRC coordinated the data cleaning. Follow-up on incomplete submissions was done by the WHO and the HSRC.

Participants from each country were asked to present, in the case of their country, (1) the process of identification and accessing of data sources; (2) the process of collating data to create the MDS; and (3) obstacles encountered in accessing, using and transferring the data.

#### 3.1. Ghana

The compilation of data for the workshop by the Ghana MDS (GhaMDS) work group was presented by David Mensah. The data sources listed in Table 3.1 could provide some of the required data, but data on the older population was found to be limited. In addition, problems were experienced with the data from these sources – most prominently that the data were often in an unreadable or a user-unfriendly format. A main problem though was the non-availability of data for different age groupings. Data are not usually provided in 5-year age groups in Ghana, which required multiple steps to be taken before analyses could be completed on the population aged 50 years and over.

A number of political and financial obstacles also contributed to delays in the release of data by government agencies. In addition, the potentially most valuable source of collected data, the 2000 Population Census, was not yet available.

**Table 3.1 Ghana Data Sources**

Date(s)*	Data source
1970, 1984, 2000	Census – Ghana Statistical Service
1993 and 1998	Ghana Demographic and Health Survey (DHS)
1997	Core Welfare Indicator Questionnaire (CWIQ)
1998/99, 2003	Ghana Living Standards Surveys (GLSS-4 and GLSS-5)

\* 2000 Census and 2003 GLSS data were not available.

The Ghana Statistical Service and the Births and Deaths Register are two of the main locations where data are stored and managed. Transfer of data from these services is

typically completed in person; distances, transportation of the data, the non-availability of personnel and time limitations contributed to delays in accessing data. These obstacles created a set of logistical and practical problems which had not been anticipated by the group. In retrospect, a formal arrangement with the agencies to access the data could have obviated these difficulties and delays.

In summary, it was noted by the group that with more time spent, more support given, and stronger co-ordination of and within the group, the data submitted for the workshop could have been more complete. Access to a resource person to discuss indicators and indicator definitions (comparing definitions suggested by the WHO to country data and data definitions) would also have been helpful and would have expedited the process of compiling and preparing data.

### 3.2. South Africa

The HSRC coordinated the compilation of the South African MDS (SAMDS), which was presented by Craig Schwabe. The HSRC had previously been commissioned by the Department of Health in South Africa to evaluate sources of data for a South African MDS on ageing (see *Ageing in South Africa. Report on the minimum data set on ageing*, March 2002. HSRC Publishers, Pretoria, South Africa. 2003.) and to make recommendations on how to populate the indicators for a baseline and in the future.

South Africa has a wealth of information sources from which it can extract data for populating the ageing MDS indicators. The main source of data accessed for ageing MDS indicators was Statistics South Africa (StatsSA); data were accessed from several sources which reside at this agency. The sources are listed in Table 3.2.

**Table 3.2. South Africa Data Sources**

Date(s)*	Data source
1991, 1996, 2001	Population census
1996 – 200	Death certificate data
1994 – 1998	October Household Surveys (OHS)
1999 – 2002	Labour Force Surveys (LFS)
1995	Income and Expenditure Survey (IES)
1999 – 2001	Mid-year estimates of the population

\* 2001 Census data not available at the time of the workshop.

Additional sources of information accessed included: The Bureau of Market Research (BMR), which conducts annual surveys from which data on population projections and life expectancy are provided. The Medical Research Council (MRC), which provides data on mortality and causes of death statistics. The US Census Bureau, which was only accessed as a last resort in cases where statistics on population estimates could not be obtained from South African departments or agencies.

The Department of Health, which provided some statistics on HIV/AIDS from its antenatal clinic surveys. The Department of Social Development, which provided information on beneficiaries from its register. The Human Sciences Research Council (HSRC), which has access to a wide variety of national opinion, HIV/AIDS and older adults surveys that provide data relevant to the MDS indicators. The University of Cape Town, which provided some information on the nutritional status of older adults.

A number of the indicators selected require that an appropriate, culture-specific assessment tool first be developed, before data can become available. As such, data were not available for a number of indicators.

In most instances, once a data set was identified, access to the data was not problematic and data from different data sources were comparable. However, a few problems were experienced in accessing data, which are categorised in three groups:

(a) **Organizational**

- Personnel were not available in departments and agencies that are the custodians of certain data sets to assist work group members with the procurement of the data.
- Numerous data sets needed to populate the SAMDS indicators had to be purchased from agencies such as StatsSA. Only in a few cases were data sets available free of charge. These data sets should rightly be in the public domain to enable decision makers to access information needed to develop policies and to implement development strategies.
- No formal arrangements were made to access data sets. To ensure that data will be provided on a regular and sustainable basis, agreements with StatsSA and other relevant government departments responsible for data sets from which to populate the different indicators are needed.

(b) **Data format standards**

- Data are stored in a format that is difficult to manipulate.
- Databases do not provide the exact data needed to populate certain indicators.
- Data can only be accessed in hardcopy format.
- Specialized knowledge (specific database or software programmes) is needed to access certain data.
- A system is needed to link data sets to corresponding metadata.

(c) **MDS indicators and/or indicator definitions**

- The equation for the assets indicator was too difficult to understand and required specialist data.
- Indicator definitions were unclear or did not match available data.
- Specialized knowledge of the subject was needed to populate certain indicators.

It was acknowledged that the compilation of the SAMDS would not have been possible without the support of the research agencies and NGOs that participated in the project. It was these organizations that mainly provided the data for the indicators. This situation contrasts with that in the other countries, where data compilation was mainly coordinated by work groups whose members for the larger part are based in government departments and

institutions. In retrospect, it was noted that consultations should have been held initially with relevant government departments and agencies to ensure effective communication and collaboration. Factors which contributed to or inhibited the collation of data for the SAMDS are listed in Table 3.3.

**Table 3.3. Factors that enabled or inhibited the creation of the SAMDS**

Enabling factors	Constraining factors
<ul style="list-style-type: none"> <li>• Data are collected routinely by Stats SA, government departments and other research institutions (e.g. the HSRC).</li> <li>• Most data sets are stored in easy to use and accessible database file formats.</li> <li>• South Africa has access to sophisticated database and cross-tabulation software (e.g. SuperCross) that optimizes its ability to extract data.</li> <li>• Several local researchers have a thorough knowledge of different data sets and indicators.</li> </ul>	<ul style="list-style-type: none"> <li>• Numerous departments and agencies that are the custodians of data have limited capacity, which makes it difficult if not impossible to access data.</li> <li>• Capacity problems result in significant time delays in the provision of data sets.</li> <li>• Data available in some sources were not totally suitable for populating certain indicators.</li> </ul>

A process of chasing data would ensure that data become available within a reasonable time frame. However, chasing data is intensive and time-consuming work. A system to access data, which is integrated in existing systems, would be more sustainable and feasible.

The main areas identified where additional work and research are required were as follows: (1) Presentation of the SAMDS results to relevant government departments and NGOs that service older clients. (2) A critical review of the MDS indicators to match South Africa's information needs and available data. (3) A reduction of the number of core indicators to enhance the sustainability of the data set. (4) Agreements entered with agencies who manage data needed to populate the core set of indicators.

Recommended actions were as follows:

- Reduce the number of indicators to a core set that reflects the priority issues of the country and at the same time enables comparisons between countries in the region.
- Clarify and consolidate indicator definitions.
- Enter agreements and/or create work plans with specialist researchers and organizations (custodians of data sets) that are knowledgeable about data for various indicators, which data may be sourced and extracted.
- Constitute a technical group that focuses on sourcing data for a specific period of time on a routine (annual/bi-annual) basis.
- Work with agencies to produce data standards/formats that are in user-friendly, cross-tabulation software that allows improved ease of use and manipulation.
- Establish regular communication between country work group members and between different country work groups.

### 5.3 United Republic of Tanzania

The Tanzanian MDS Project (TanMDS) work group co-ordinated the compilation of data for the workshop, which was presented by Peter Bujari. The multi-disciplinary work group comprises colleagues in the National Bureau of Statistics, HelpAge International Tanzania, the Ministry of Health, the Ministry of Welfare, the President's Population Unit, local universities, WHO Tanzania and TAMWA.

What is interesting in Tanzania is that according to projections based on the 1988 Population Census data, the percentage of persons aged 50 years and over will have decreased by 2002 (Table 3.4). The projections need though to be compared with the results of the 2002 census, when the data become available.

**Table 3.4. Age structure (%) of Tanzanian population 50 years and over, 1998 and projected for 2002**

Age group (years)	Year	
	1998	2002
	%	%
50 – 54	2.67	2.27
55 – 59	2.01	2.01
60 – 64	1.90	1.63
65 – 69	1.35	1.12
70 – 74	1.21	0.92
75 – 79	0.62	0.51
80+	1.07	0.44
Total	10.84	8.90

Source: 1988 Population Census, NBS.

The Tanzanian National Bureau of Statistics (NBS) is a major source of data. Following on the Statistical Act of 2002, the NBS has drawn up a National Statistics Plan for official statistics. Due to different governmental and administrative structures, data collection efforts in Tanzania mainland and Zanzibar have not been co-ordinated. However, NBS has now started to co-ordinate all data collection in the Republic. The NBS is the main data warehousing agency, and establishes statistical standards and co-ordinates statistical activities in the country. Data sharing is actively encouraged, which is strengthened by a provision that allows joint data collection by NBS and any government ministry, department or agency.

The NBS produces the Tanzania Socio-Economic Database (TSED), which is both a database and a database management structure. Raw data may be accessed from the TSED and tabulations made from the input data sets, which include all metadata. A module for the MDS will be created for and included in the TSED.

The TanMDS work group has agreements with various ministries, through the NBS, to access different data sets. No major problems were experienced in accessing or collating data. Data sources accessed to compile the MDS are listed in Table 3.5. Data for some indicators could not be generated from existing data sources. TanMDS had agreements with various Ministries, through the NBS, to access different data sets. No major problems accessing or collating data were encountered.

The NBS produces the Tanzania Socio-Economic Database (TSED), which is both a database and database management structure. From TSED, one can access raw data and can produce needed tables from the input data sets. It includes all metadata. A module for the MDS will be created for and included in the TSED.

**Table 3.5. Tanzania Data Sources**

Date(s)*	Data source
1998 and 2002	Population and Housing Census (q10yrs)
2000/01	Household Budget Survey (q5yrs for mainland)
2002	Tanzania Reproductive and Health Survey (qyr for mainland)
2002	Health Statistics Abstract (qyr for mainland)
2000/01	Integrated Labour Force Survey

\* 2002 Census data not available. Future data sources include: 2003 & 2008 Agricultural Surveys; 2004 & 2009 DHS; 2005 & 2010 Labour Force Surveys; and 2006 & 2011 Household Budget Surveys.

With advanced planning and agreements in place, the TanMDS work group should in future be able to work with colleagues to collect data from national surveys scheduled annually in Tanzania (e.g. the 2004 DHS). Synergies with scheduled data collection efforts could be identified and optimized. An opportunity might also arise to add an ageing and older adult health module to future national surveys.

### 3.4 Zimbabwe

The Zimbabwean MDS Project (ZimMDS) work group, co-ordinated by colleagues at the University of Zimbabwe, compiled data for the workshop with the assistance of the Central Statistics Office. The group's work was presented in the workshop by Sebastian Gavera. Data management is the responsibility of the ZimMDS Secretariat.

Sources of data accessed in the compilation of data for the ZimMDS are shown in Table 3.6. The Ministry of Health and Child Welfare, and the Central Statistics Office were the main sources of information. Additional data sources were vital registration and NGO-based research.

**Table 3.6. Zimbabwe Data Sources\***

Date(s)*	Data source
1992,2002	Census
1995	Poverty Assessment Study
1997	Inter-Census Demographic Survey (ICDS)
1999	Demographic and Health Survey (DHS)
2001	Human Development report

\*The Ministry of Health and Child Welfare and the Central Statistics Office are the main sources of information. Additional data sources: Vital registration; NGO research.

A number of issues concerning available data sources and gaps in available data are listed in Table 3.7 below.

It was suggested that a coordinating body, e.g. the Central Statistical Office, could be a solution to improving the availability and accessibility of usable data in Zimbabwe. It was noted that additional human resources are needed within government departments to manage data. For example, the Ministry of Health and Child Welfare currently has only one person who manages all data. Apart from the procedural difficulties in accessing available data, the relative lack and poor quality of the data indicate a need for a survey on ageing in Zimbabwe.

**Table 3.7. Zimbabwean issues with data sources and gaps**

Data sources	Data gaps due to:
<ul style="list-style-type: none"> <li>• Other data sources include: research papers for academic institutions, organizations and individual researchers; administrative records; private organizations such as senior citizens clubs, medical aid societies and pension funds.</li> <li>• Available data were often in an unusable format and incomplete.</li> <li>• Data from government reports are often not broken down as defined for the MDS indicators, e.g. no data are available for the 80 years and over age group. Primary data very difficult to access.</li> </ul>	<ul style="list-style-type: none"> <li>• Bureaucracy - accessing available data very difficult, in large part because of the 2001 Official Secrecy Act.</li> <li>• Manpower shortages - high staff turnover, and a great deal of raw data but no continuity in analysing and managing the data.</li> <li>• Limited data on the non-institutionalized older population.</li> <li>• Access to needed technology, e.g. software and the web.</li> </ul>

In addition, fostering and supporting a research culture and researchers would be a step towards addressing the need to fill data gaps. A research community that followed an established structure, utilized administrative records to improve national coverage and encouraged data sharing was identified as desirable. Addressing a number of basic issues – data collection and formatting standards, technology improvements and training, and a stable workforce – would decrease barriers to accessing and using data.

Differences in available software and hardware made data transfers a challenge (some governmental departments do not have access to the internet). High staff turnover in many of the departments that provide information often results in delays in releasing the data

because the data have not been properly checked and analyzed according to existing requirements. Job insecurity and staff turnover results in poor continuity from data managers. In addition, the system of requesting access to data is highly bureaucratic and slow.

Strategies to overcome obstacles were identified as follows:

- Set-up a stronger, intersectoral ZimMDS work group that is well co-ordinated. The work group should have resources to meet regularly to synchronize activities.
- Strengthen the national 'Council for the Elderly in Zimbabwe' and give it more authority and resources.
- Publicize the need to analyze and standardize existing data – then initiate the process of analyzing and harmonizing available data.
- Continue attempts to combine data resulting from qualitative and quantitative studies.
- Establish a coordinating data management agency which sets data collection and management standards, particularly regarding administrative records such as coding death records.
- Create a policy on older adults, which would help to address some of the practical information and data needs.

It was noted that meaningful use of data by the government will occur when the government uses the data to inform the development of a policy on older adults. The Ministry of Labour and Social Welfare has in fact requested data from the ZimMDS for this purpose and a policy document has been drafted.

### **3.5. MDS Version 1.0 – combined countries**

The MDS Version 1.0 for the countries combined was presented by Craig Schwabe. Version 1.0 includes available data for the four participating country, with corresponding limitations of validity, reliability, comparability and completeness of the data in each case.

The WHO, with assistance from the HSRC, facilitated the completion of the identification and access of available data sets, the collation of data and metadata for each collaborating country, and the preparation of both the data and metadata for presentation in the workshop. The procedure followed was as follows:

1. Using established indicator definitions (including data units and criteria), the WHO and the HSRC assisted the collaborating countries with the collation of known available local data. The process was facilitated through guidelines for the inclusion of data from different data sources, suggested data formats, spreadsheets for data entry, and instructions about the format/process for transmitting data (materials available on request). The HSRC, in consultation with the WHO, defined the suggested format for data submission. A suggested format for metadata submission was also transmitted.
2. The above materials and instructions were disseminated by email and/or fax. Follow-up and technical assistance was done through regular e-mail contact and, where needed, personal communication.

3. Submitted country data were reviewed and integrated into a single spreadsheet. However, the provision of indicator definitions meant that, the process was slowed down by differences in units and categories. As far as possible, the data were standardised, but in some instances were simply added to the spreadsheet, to reflect that data had been received but did not match the required categories for the indicator. A best estimate value for each indicator and each country was used. Data were cleaned and discrepancies/gaps were identified. All data were then verified with colleagues in each country. Where relevant, data were compared to data available from international sources (e.g. WHO, UN Population Division, and the US Census Bureau).
4. Data received from the countries were imported into a relational database and archived at the HSRC. All data remain the property of each country, but are in the public domain unless other instructions were given. Countries provided only a single value for indicators in a spreadsheet or MS Access file format, rather than submitting values from different data sets or full data sets for a relevant indicator. The full data sets from which best estimates for indicators were derived remain warehoused and managed in the country of origin.

It was noted that new international and regional policy frameworks, e.g. the UN Millennium Development Goals, the UN International Plan of Action on Ageing, and WHO's Health Metrics Network (Strategy on a Long-term Development of Core Health Indicators) warrant review, and a streamlining of the MDS indicators to align them more closely with these larger mainstream processes was needed. This process may be a way to work more closely with countries, to minimize the increasing demand for data for indicators. Working with countries on the MDS Project and the WHS Programme, the WHS instrument will be used to improve the amount and quality of health and health-related data through collection of high quality household data on persons aged 50 years and older, including self-reported assessments of health linked to anchoring vignettes for improved comparability across individuals, communities and populations.

### **Data gaps**

The table in Annex 2 show indicators for which data were available by country at the time of the compilation. For the 44 indicators in the MDS Version 1.0. The available data falls mainly in the area of demographic information and social and economic information (from censuses predominantly and some surveys). Even with these categories of information, comparability remains a major issue due to the use of different units of measurement and different categories. For example, each country had a different set of categories to describe marital status, which means that each country has a unique set of values for this indicator. Agreed standards for harmonizing data are needed.

The compilation of Version 1.0 of the MDS highlighted the almost total absence of comparable data on the health status of older adults, on their use of health services, and on risks and determinants of mortality. The following two sections focused on addressing these gaps through the implementation of the World Health Survey in a large number of African countries and on through an examination of strategies to improve information on adult mortality in African countries.

**Next steps**

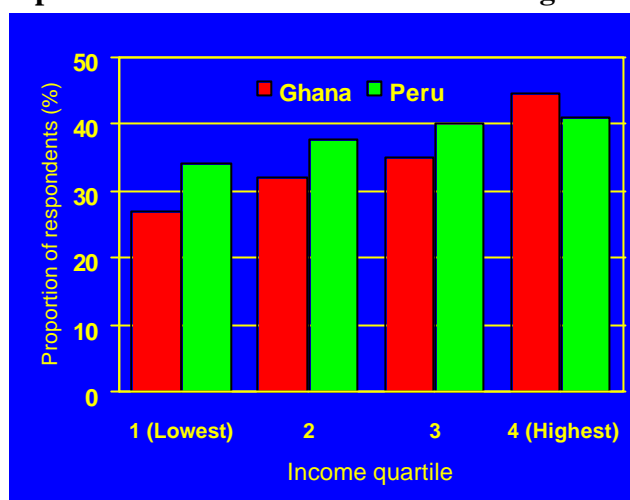
Discussion in the workshop towards the finalization of the first phase of the MDS Project resulted in agreements on the following steps: (1) Finalization of the MDS Version 1.0; (2) Development of a strategy for the dissemination and use of the MDS Version 1.0 in the four participating countries, particularly to inform policy on older persons in Africa; and (3) Revision of the MDS Version 1.0 indicators to reflect mainstream national processes, such as the PRSPs and the MDGs, to link them more closely to countries' information needs and capacities.

Suggestions for further use of MDS Version 1.0 at country level:

- To compare data within and between countries in a series of country and cross-country briefing papers, reports and publications. Use of the MDS to inform discussions about evidence for policy.
- To use data collected for the MDS Version 1.0 for further research, policy formation and advocacy purposes.
- To fill and eliminate data gaps, by (a) prioritizing which gaps should be filled in the short, medium and long term; (b) using data yielded by WHS and INDEPTH to fill gaps; and (c) strengthening national health information systems and involving local agencies, including WHO country and regional offices and NGOs.
- To work with WHO to develop an indicator review process, including data criteria and standards for indicators, as outlined by the Health Metrics Network. The review should include both a core and expanded set of indicators relevant to the country's information needs and capacities, as well as specific data issues, inclusion criteria, standard units and definitions, and suggested sources and mechanisms for data collection.

**4. Ongoing Data Collection Efforts –****4.1 Comparable measurement of health status**

A number of paradoxical findings have been reported in analyses of population health surveys, suggesting that self-reported health measures may give misleading results if differences in the way people use question responses are not taken into account. Figure 4.1 illustrates this using data on reported illness in the last month among adults from Ghana and Peru (Murray and Lopez 1996). In both studies, the wealthiest groups report more illness, in contrast to other available information on the relationship between illness and socioeconomic status. There is considerable evidence that perceptions and labelling of health and illness vary across social groups and countries.

**Figure 4.1 Reported illness in the last month among adults aged 15-39**

This evidence has been ignored by many who use self-report survey measures of health status to report on population health, health inequalities or intervention outcomes. Most effort has gone to make instruments and/or questions comparable and survey methods identical. This does not solve the basic problem: lack of comparability in use of ordinal response categories.

Survey developers have emphasized the importance of establishing the validity of instruments and their reliability, but until recently, little attention has been paid to the issue of cross-population comparability. The latter relates fundamentally to unmeasured differences in expectations and norms for health, so that the meaning different populations attach to the labels used for response categories in self-reported questions, such as mild, moderate or severe, can vary greatly. Recent developments in survey methodology using measured tests and anchoring vignettes to calibrate self-report health questions hold considerable promise in addressing this problem (Murray, et al. 2002., Murray, et al. 2003.)

Anchoring vignettes are short descriptions ('vignettes') that mark fixed levels of ability (e.g. people with different levels of mobility such as a paraplegic person or an athlete who runs 4 km each day). Survey respondents are asked to rate the vignettes for a health domain using the same question and response categories as for their self-report on their own level of health, allowing the calibration and comparison of the self-report responses.

Measured tests and anchoring vignettes were included in the WHO Multi-country Survey Study (MCSS) 2000-2001 (WHO 2002), which served as the development platform and assessed health and other health-related topics in representative populations in 61 countries (Ustün, et al. 2003.). A total of 71 surveys were undertaken in those countries. Unfortunately, only one African country, Nigeria, was able to collaborate in the MCSS. The WHO MCSS aimed to address critical methodological questions to develop valid, reliable and comparable instruments and to test the validity of different modes of survey implementation including long-form household, short-form household, self-administered postal and computer-assisted telephone interviews. Results from the WHO MCSS in 69 countries provided clear evidence that different populations, and groups within populations, use response categories differently to describe the same health states.

Valid, reliable and comparable measures of the health states of individuals are critical components of the evidence base for health policy. They are crucial for the measurement of health outcomes in clinical trials and the development of summary measures of population health, so a strategy of including vignettes in national health surveys and clinical research may contribute to improving the interpersonal and cross-population comparability of these measures. Based on the WHO MCSS 2000-2001, and the extensive survey experience in the Member States, the World Health Survey (WHS) was developed in collaboration with Member States, and a concerted effort was made to identify collaborating groups in African countries, in order to address the gaps in health information in Africa identified in the MDS Version 1.0 (see Section 3 above).

#### **4.2 The World Health Survey (WHS)**

A brief overview of the World Health Survey (WHS) was presented by Margie Schneider. The WHS has been created to address two major challenges facing health policy-makers at the national and international levels: (1) the need for reliable information to be able to improve the health of the populations which they represent; and (2) the increase in resources committed to improving health in all settings as a result of the impact of increased international and national attention to the role of health in human and economic development. To address these challenges, WHO is using nationally representative health surveys to provide high quality baseline information on the outcomes associated with the investment in health systems, baseline evidence on the way health systems are currently functioning, and/or a strategy to monitor inputs, functions, and outcomes.

Although national Health Information Systems (HIS) can provide some of this information, in many cases, it does not have the capacity to provide sufficient valid information that is comparable across populations. National and sub-national level surveys can supplement these data to facilitate the monitoring of health status and health systems while creating the baseline information required.

##### ***Objectives of the WHS***

1. To develop valid, reliable and comparable household survey modules in a cost- effective manner with proper quality control.
2. To form links with national, international and regional networks for sub- national, national and regional needs.
3. To provide a dynamic data collection platform with a transparent audit trail and availability of data in the public domain as an international public good.
4. To facilitate the use of evidence in appropriate strategic planning, programme management, monitoring and evaluation with particular emphasis on the monitoring of Millennium Development Goals and on the critical outcomes in the poor.
5. To test the feasibility of using the WHS as a platform for longitudinal study of ageing and older persons in selected countries, including three in sub-Saharan Africa.

##### ***Implementation of the WHS***

The World Health Survey offers a menu of choices covering the following areas: 1) health states measured in multiple domains; 2) risk factors (e. g. tobacco, alcohol, pollution); 3)

responsiveness of health systems; 4) coverage of key health interventions; 5) health care expenditures: how much households contribute to health care; and , 6) mortality: adult, maternal and child. In addition, countries can flexibly add on additional modules on Community Health Insurance Programmes, Human Resources for Health, Social Capital or other modules that are of particular local interest. The WHS has been developed to address cultural sensitivity. A number of different techniques have been introduced to calibrate the self-reports of individuals on their own health and on how they are treated by the system.

### ***Health state measurement module***

Two key aims for the health state measurement module in the WHS pilot tests (included in six of the 12 pilot studies) were (1) to extend the set of six health domains included in the prior MCSS (mobility, self-care, usual activities, pain, affect and cognition) in order to cover a broader range of important components of health; and (2) to evaluate a large number of anchoring vignettes on each domain in order to select a subset of vignettes with the best performance for inclusion in the WHS. In addition to the six domains used in the prior study, the WHS included vision, hearing, breathing, sleep, energy and interpersonal relations, to bring the total number of candidate health domains to 12. For each domain, at least two survey items were tested, and a set of 15 different vignettes per domain were used, rated directly with all items on a given domain.

A range of different evaluative criteria were used to compare domains, items and vignettes, including: (1) location of estimated vignette levels relative to estimated categorical thresholds for a particular item (for efficiency vignettes should be located near thresholds and spaced evenly across distribution of values for a domain); (2) variance of specific vignettes (lower variance is one indication that vignettes are being interpreted similarly by different respondents, which is a requirement of the analytical model used for anchoring vignettes and self-assessments); (3) consistency in rank ordering of different domain items in distributions of both self-assessments and vignette ratings; (4) relative contributions of different domains to overall health state valuations; (5) correlation of individual rank ordering of vignettes to overall average rank orderings; (6) independence of self-assessments on different domains (domains that are highly correlated with others add little additional information on overall health levels).

Based on these criteria, eight domains of health were selected for the 2002-2003 round of the WHS (mobility, self-care, vision, pain, affect, cognition, sleep/energy and interpersonal activities). For each domain, two items were included in the final survey instrument, and five vignettes were selected.

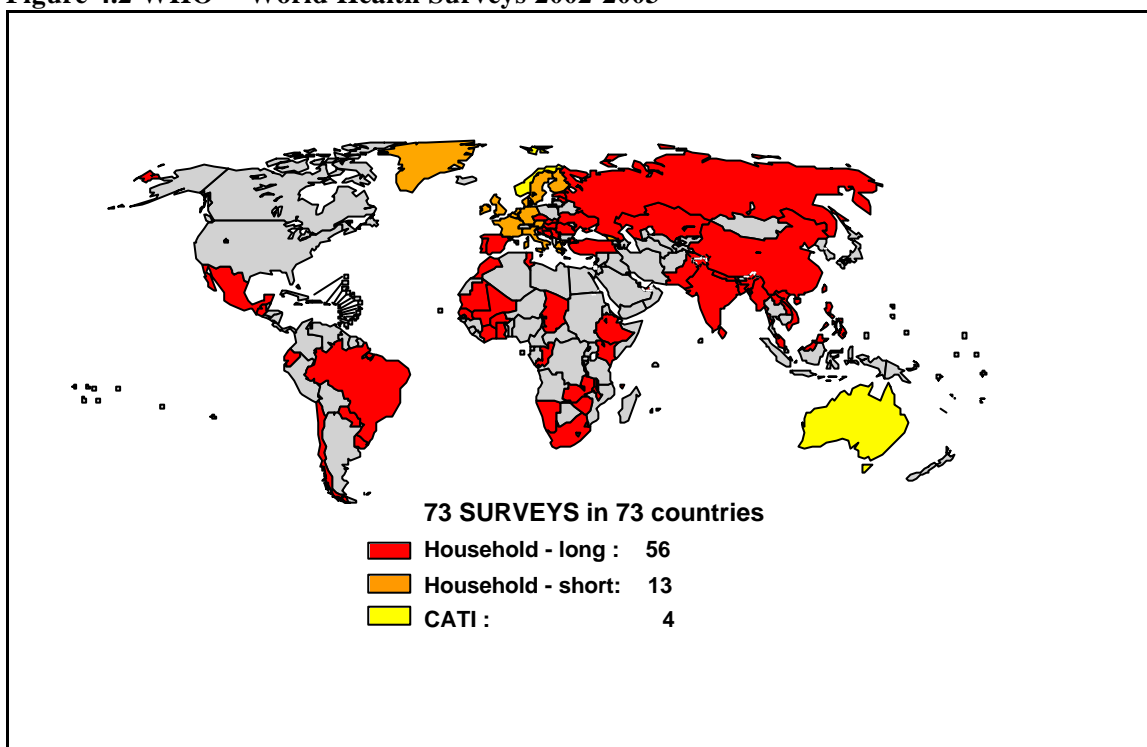
### ***Sample size***

Responses should be representative of the population if they are to be useful for policy. Depending on the needs of each country, sample size may vary between 1000 and 10,000 for each country survey. Respondents will be randomly selected. The first phase of the work covers adult populations (i. e. older than 18 years of age). An oversample of respondents aged 50 years and older has been added to eight countries – three in sub-Saharan Africa. Additional follow-up planned in selected countries will focus on the health of persons aged 50 years and older.

### *Interaction with Countries and HIS*

The WHS Survey Programme has been developed in individual countries through consultation with policy-makers and in collaboration with the people involved in HIS. It is complementary to their efforts, to ensure periodic data input in a cost-effective way so that important gaps in health information are covered. It will also establish a baseline for efforts to scale-up health activities. The survey data will provide data that will enable a comprehensive analysis of health and poverty issues and track the impact of programmes on reducing inequalities. Seventy-three countries are presently carrying out the survey distributed across the six WHO Regions (Figure 4.2).

**Figure 4.2 WHO - World Health Surveys 2002-2003**



Eighteen countries in sub-Saharan Africa are working with WHO in this round of the survey as listed in Table 4.1.

**Table 4.1 African countries participating in the WHS 2002-2003**

<b>Francophone</b>	<b>Anglophone</b>
Burkina Faso	Ethiopia
Chad	Ghana
Comoros	Kenya
Congo (Brazzaville)	Malawi
Côte d'Ivoire	Namibia
Mali	South Africa
Mauritania	Swaziland
Mauritius	Zambia
Senegal	Zimbabwe

\* See [www.who.int/whs](http://www.who.int/whs) for a description of the regions and a list of participating countries.

WHO provides standardized, pre-tested survey modules; technical support and assistance on survey implementation (through training workshops and materials, and technical experts assigned to countries to support survey implementation and data analysis); quality assurance guidelines which set standards for the WHS; training workshops in data analysis; and a forum for discussion on policy implications.

An emphasis has been placed on capacity-building of local researchers to undertake and analyse surveys in conjunction with health information systems, and to work with national, regional and international partners in this regard. The WHS is WHO's platform for data collection and will continue to be improved and harmonized with national systems.

### ***Logistical problems***

Implementing surveys in any context is difficult. The experiences gained in implementing the WHS in Africa are part of a feedback loop to improve skills and ease the process of data collection, collation and analysis. A summary of logistical problems follows:

- Skilled colleagues, but too few in number
- Dated sampling frames – adds extra time and money for listing enumeration areas
- Remote locations and seasonal barriers (rainy season)
- Insecure areas as a result of armed conflicts/political instability
- Poor communication networks
- Additional time it takes to work with local traditional leaders/block chiefs
- Language and translation
- Length of questionnaire
- High material, service and transport costs
- Lack of basic materials: paper, electricity

### ***Longitudinal add-on to WHS surveys***

The WHS will provide health and health-related data on older persons and will be used as a platform for longitudinal study of this population. Three countries, Ghana, South Africa

and Zimbabwe, will be included in annual longitudinal follow-up for at least two rounds, providing much needed data on changes, trends and patterns in health status.

We aim to draw on experiences from other longitudinal aging studies in enhancing successful follow-up during the planned consultations for the development of the aging module. Although experience in longitudinal ageing studies is limited outside of industrialized countries (for example, a recent review of various longitudinal ageing studies included no studies in developing countries: [http://www.cihr-irsc.gc.ca/institutes/ia/news/longitudinal\\_studies\\_e.shtml](http://www.cihr-irsc.gc.ca/institutes/ia/news/longitudinal_studies_e.shtml)), we can also draw lessons from the larger body of qualitative research that has been conducted in Africa and elsewhere (for example, HelpAge International, 2003).

Our present plan to minimize losses to follow-up from drop-outs, withdrawals, migration/change of residence or administrative reasons (e.g., incomplete data), and to account for attrition (replacement for deaths), consists of several components.

Firstly, the WHS accounts for residential status and migration in the standard household questionnaire. In addition, the WHS currently asks respondents for the name of one relative/contact with detailed coordinates to be used when respondents cannot be located for re-testing – a similar strategy may be used for annual follow-up in the longitudinal study. We will also request information about employers and health services utilized, which would offer additional information to aid in follow-up.

Secondly, the WHS is combining new technologies (GPS) with more traditional techniques derived from qualitative research studies (for example using key informants, community leaders and community level follow-up). Contact details for households will be supplemented with GIS codes in all surveys in this proposal, and other relevant country-specific measures will be applied when available. For example, in South Africa, we will work with CASE (Community Agency for Social Enquiry) and the HSRC (Human Science Research Council) in using the South African Master Sample to track respondents. The Master Sample includes a sample of the 2001 Census stratified by province and enumeration area (adjusted to reflect the representative population subgroups). Each of the 1,000 enumeration areas have aerial photographs of households plus GIS coordinates.

Finally, we propose to take advantage of DSS sites that are members of the INDEPTH network (where overlap exists). DSS sites are unique in that they have a continuous presence in the community (although they are not specifically focused on older populations). We have begun discussions to link the WHS to selected INDEPTH member sites. In these cases, we plan to make use of contacts with key informants in the community at the time that the survey is conducted and to notify them, as well as the respondents, that we intend to conduct follow-up interviews in one year. When possible, we will also link health or administrative data to the WHS for respondents who are participating in INDEPTH member sites.

The addition of a longitudinal component to the current plans for the WHS will enable the assessment of health changes over time on an individual basis and direct linkages between

non-fatal health experiences and mortality in settings where these types of data are limited. Of particular value will be the collection of longitudinal data on aging populations in developing countries using standardized instruments designed to enhance cross-population comparability.

For further information, visit the WHS website at: <http://www.who.int/whs>

### **4.3 INDEPTH**

Philip Setel presented a brief overview of INDEPTH and AMMP. An International Network of field sites with continuous Demographic Evaluation of Populations and Their Health in developing countries (INDEPTH), was created to bring together community-based longitudinal demographic surveillance initiatives in resource constrained countries.

The goal is to provide a better, empirical understanding of health and social issues, and to apply this understanding to alleviate the most severe health and social challenges. To accomplish this goal, the network is working to:

- Initiate and facilitate cross-site, longitudinal health and social studies and impact assessments in severely resource constrained populations.
- Disseminate study findings to maximize impact on policy and practice.
- Broaden the scope of health research by confronting the emerging agenda of non-communicable disease and ageing, violence and injury, migration and urbanization and the problems associated with vulnerable population segments.
- Continually improve the methods and technologies used by member sites to ensure all participating groups have access to the most valid and appropriate methodologies available.

These sites are a valuable source of longitudinal data health and well-being of older persons.

In addition, they are working to provide a standard set of validated tools and methods to investigate adult morbidity and mortality in developing countries. The number of older persons in a DSS site is bounded by the site size and the geographic demarcations – and thus the representativeness of the data needs to be established. Close integration into national data collection efforts and clearly defined outcomes and messages for policy and programmes are two distinct strengths of the Network sites.

#### ***Tanzania Adult Morbidity and Mortality Project***

Twenty-four sites in 12 countries in sub-Saharan Africa are members of the INDEPTH network. Details of one site, the Tanzania Adult Morbidity and Mortality Project (AMMP), illustrate the potential for working with countries to use existing data collection infrastructures and data on older adult populations.

Since the early 1990's, information about mortality in Tanzania has come from a combination of routinely collected data sources, such as the health management information system, vertical programmes (for example, tuberculosis, leprosy and AIDS control), demographic surveillance sites, censuses and national surveys. While in theory, the resulting data should have provided a picture of adult mortality, no reliable sources of total or cause-specific adult mortality were available in Tanzania before the mid-1990s. The vital

registration system was non-functioning and the census results from 1988 were now of limited utility – particularly in light of the subsequent impact of HIV/AIDS. No other major population-based efforts were undertaken to investigate the levels of adult mortality or burden of disease.

Starting in 1992, the Ministry of Health, in partnership with the University of Newcastle upon Tyne, established the Adult Morbidity and Mortality Project. Support was from the UK Department for International Development. The objectives of the first phase of the project were to: 1) define causes and rates of mortality in urban and rural living adults; 2) explore causes of and conditions related to adult morbidity and mortality; and 3) provide information with policy relevance. This effort filled a data gap in adult mortality using demographic and mortality surveillance.

In its second phase, AMMP worked within the context of the new National Health Information to support the development of a sustainable National Sentinel Surveillance system of linked DSS sites for the production of community-based health information. In order to accomplish this, the project sought to: 1) generate and disseminate information from sentinel demographic surveillance sites; and 2) produce representative burden of disease poverty estimates for policy, planning, monitoring and evaluation at district, regional and national levels.

Demographic surveillance methods provided certain advantages for generating adult morbidity and mortality data compared to administrative data collection systems, censuses and national surveys. The continuous monitoring in a defined population significantly increased the quality of the outcome data. For example, the burden of disease for the population aged 60+ years (as assessed through disability adjusted life years), was calculated to be 80% from non-communicable diseases. This indicated that 91% of disease burden in this population was due to conditions needing longer-term care and management. From 1992 through 2001, the project recorded over 12,400 deaths to adults aged 50 plus. These data will provide an excellent insight into mortality conditions in this age group.

## **5. Adult mortality data sources and data collection systems**

As noted in Section 3, basic information on mortality risks for older adults is unavailable for most African countries. The workshop devoted a number of sessions to an examination of the existing data sources and systems for measurement of older adult mortality in African countries, in an examination of the factors involved in improving death registration data in several African countries which have had some success in this area, in reviewing other potential approaches to the measurement of adult mortality in African countries, and in developing recommendations to address this crucial data gap.

### **5.1. Background**

Statistics on mortality are primary inputs for computing summary measures of population health for local and national policy and planning purposes. It has been noted for decades that adult mortality rates are highly desired and needed, particularly with the knowledge that populations in sub-Saharan Africa are ageing at a faster rate than those in developed and other developing countries (US Census Bureau International Data Base, 2003). Disease

specific mortality rates are also extremely useful feedback for monitoring specific health programs, and for identifying and prioritizing health research activities. Paucity of data from countries in Africa has impeded informed health care policy development and health service delivery planning in the entire region, which is currently in the midst of demographic, epidemiologic, socio-economic and political transitions. These can serve two main purposes, to provide a basis for policy development, as well as to measure and monitor the impact of these policies. Model-based estimates, while acceptable for the former, cannot substitute locally generated data for the latter function.

Considering that adult mortality data are sparse for many countries in sub-Saharan Africa, regional and national planners have had to depend on model-based estimates of population, fertility, and mortality. The empirical data used as inputs for these models are of variable quality and quantity, and the resulting outputs, at best, serve as benchmarks to guide policy and planning in a broad context. High quality data from the local level are essential for getting an accurate picture of population health status. Yet, while routine systems of birth and death registration are the preferred mechanisms for generating valid and reliable fertility and mortality statistics, only a few countries in sub-Saharan Africa have a registration system – and even fewer produce timely data with sufficient coverage.

A common response to calls for improved data is that generating nationally representative data from civil registration systems in Africa is difficult, from both administrative and technical perspectives. Most countries in the region have regained independence as recently as during the past 50 years and are striving to establish public systems for governance and health. The HIV/AIDS epidemic and armed conflicts in the last decade have further crippled the region, and has pushed the health and socio-economic status of its populace to possibly their lowest levels in history. A recent estimate from the WHO places the average life expectancy at birth for some countries in sub-Saharan Africa as low as 37 years (WHO, 2002). A sound strategy would be to (re)verify these estimates using valid and reliable local data, which, if obtained through a routine data collection system using civil registration procedures, can also serve the long-term purpose of monitoring these vital events and health status indicators.

In this workshop, mortality data, data sources and collection systems were reviewed. Relevant WHO databases and other data collection efforts that have attempted to measure fertility and mortality were explored. Existing legal frameworks and administrative structures of civil registration systems in nine countries in the region were presented. We heard the success stories of data collection in South Africa and Zimbabwe, with a view to identify best practices from which other countries can find common ground. We discussed the use of Sample Registration Systems (SRS), as implemented by India and China, as an interim measure to obtain the desired data. We considered the use of verbal autopsy methods and available hospital statistics to derive a national level picture of the cause specific distribution of mortality. Finally, we documented our understanding of the situation at present, and our recommendations for the future, setting as a goal the establishment of national systems that will routinely provide valid and reliable data on fertility and mortality.

## **5.2 Mortality data sources and access**

A summary of discussions about data sources and access to these various data sources follows. Unfortunately, beyond the general lack of good quality data (with some notable and acknowledged exceptions), knowledge about the existence of a data source and access to those data may not coincide and was identified as a significant problem.

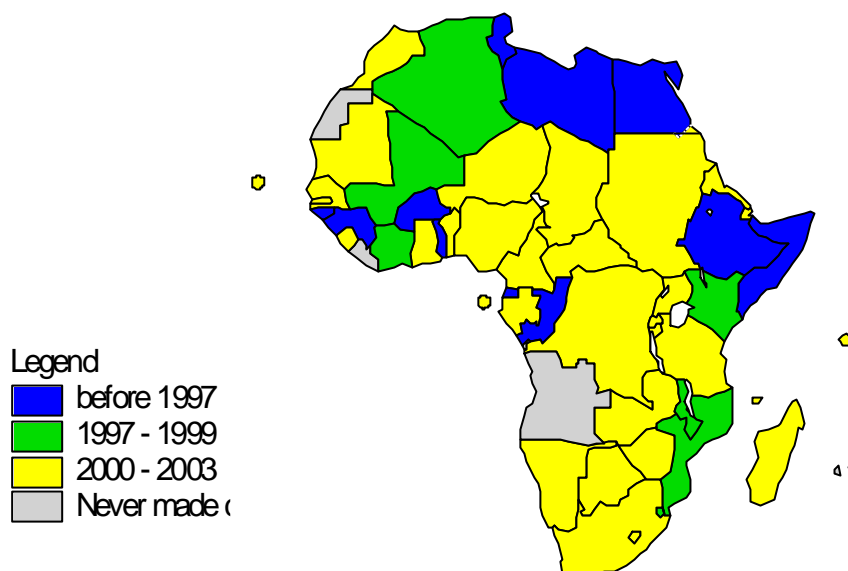
### ***Census data collections***

Population and mortality statistics are routinely maintained by Ministries of Home Affairs (or similarly named institutions) at national level. These data are collected during decadal census rounds, and are supplemented by statistics from registration of births and deaths from the various administrative divisions within the country. The U.S. Census Bureau maintains a database that informs about completed and projected census rounds in all countries of the world. Figure 5.1 shows the details of latest census round conducted in each country in Africa.

While national census rounds usually involve population counts, with some associated demographic and possibly socio-economic details of citizens, some countries include questions pertaining to mortality, either in the form of (a) birth survival history from women in maternal ages, (b) deaths within the household in the 12 months preceding the census, (c) survival history of parents, or (d) sibling survival history. It is necessary to explore the availability of such data, and to attempt to derive measures of child and adult mortality from these data. Such estimates can serve as alternate data points to compare with the currently available model-based estimates and assess their plausibility.

Countries marked in yellow in Figure 5.1 have conducted or are conducting census rounds during the period 2001-2003. This provides an overview of currently usable census data from Africa, the uses for which will be explored later in the report. Countries that have planned a census during 2003 have been included, with hopes that the data will be available sometime over the next two years. It is encouraging to note that many countries in Africa will have conducted a census in the most recent period, and some of the remaining countries have census rounds planned during 2004.

**Figure 5.1. Latest year of census** (Source: U. S. Census Bureau, International Data Base (IDB) 2003. <http://www.census.gov/ipc/www/cendates/cenafric.html>).



Assessments of census data for coverage and completeness are extremely important, and to a large extent determine the usability of the data. In general, countries run sample recounts to cross check the original dataset. It would be useful to study reports that detail both the mechanisms and the results of such recount exercises, to understand the quality of the census data, and to understand the validity of the final census population counts. In normal circumstances, there is a two-year lag period between census data collection and availability of the final estimates. It is generally understood that data from census rounds can be used as a sampling frame for drawing nationally representative population samples within three years of the conduct of the census. After this period, the data ceases to be truly representative, on grounds of changes in population counts due to births and deaths, and more importantly, inward and outward migration. Colleagues conducting research in Ghana have reported high migration rates have already minimized the utility of the 2000 Census enumeration. As supported by this example, a small window of opportunity exists for some of the important uses of census data. This is discussed in more details in the recommendations on sample registration systems later in the report.

### ***Demographic and Health Surveys (DHS)***

In the absence of adequate data from national civil registration systems, and to meet the requirement of obtaining data on some critical indicators of population health such as infant and child mortality, the U.S. Agency for International Development (USAID) set up a system of conducting Demographic and Health Surveys (DHS) in developing countries. The *modus operandi* involves detailed household surveys on a nationally representative sample of about 5000 households. The survey instrument is modular in format and includes a module on birth history of women in the maternal age group, recording the outcomes of each

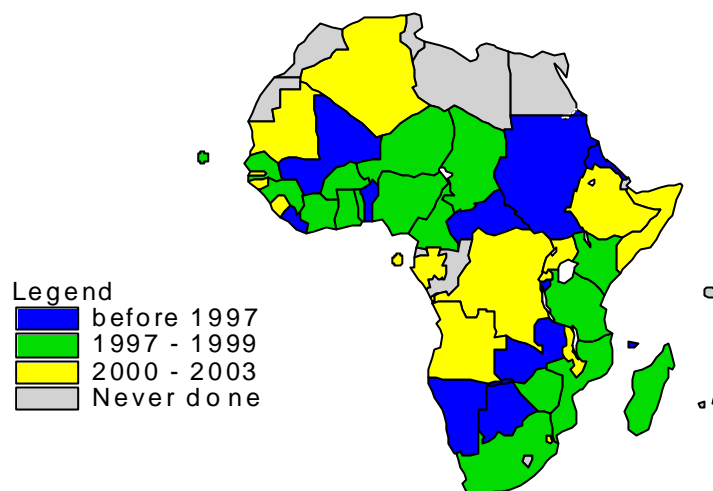
pregnancy and survival history of live births. Estimates of fertility, infant and child mortality can be computed within reasonable bounds of uncertainty and have proved invaluable for policy development and monitoring. A few recent surveys have added verbal autopsy questions to ascertain the causes of infant and child deaths. However, a standard verbal autopsy approach has not been used thereby reducing the usability of subsequent cause of death data.

In addition to birth history, modules to ascertain sibling survivorship of adults have been also tried to assess maternal mortality and levels of adult mortality. These indirect measurements of mortality are subject to wide margins of uncertainty. The use of these data is at an experimental stage and needs further testing, so developing routine data collection systems remains the best option for sustainability.

The DHS also includes modules on access and utilization of antenatal care, early childhood health and immunization, and other important socio-economic parameters related to health and health care. In general, the survey is conducted in about 10 countries every year, and on an average, the survey is repeated in a country about once in five years. The surveys are costly, as much emphasis is laid on data quality, owing to the small sample size being used to estimate indicators at the national level. Despite the good quality of the data, the resultant estimates may not be reliable at the local level because of the small sample sizes. Also, some results may not be plausible. For instance, in India the estimate of infant mortality rates from DHS (called the National Family Health Survey (NFHS) in India) is lower than that computed from data obtained through the SRS (discussed later).

While the DHS do provide a valuable source of data, public health experts are more inclined to accept an SRS estimate than the NFHS estimate, owing to three main factors: 1) larger nationally representative sample sizes in the SRS; 2) estimates from SRS are based on continuous enumeration of births and deaths within a selected sample population, while the NFHS is a one-off household survey; and, 3) methods exist to reduce biases in SRS (accounting for missed events in routine registration through independent resurveys or by using standard demographic techniques for assessing completeness of registration) where in contrast, recall bias in DHS is a problem for which one cannot easily make adjustments.

Figure 5.2 shows the latest rounds of DHS conducted in African countries. These data have been used to compute levels of child mortality, that have further served as inputs in the life table prediction models used by the WHO to compute national and regional estimates of mortality by age and sex. In the absence of other data from the region, these surveys have been invaluable in filling in the data gaps, but the time has come to move on from one-off, costly and intensive surveys to routine, continuous data collection systems in order to address the need for information on adult mortality, as will be described later in the report.

**Figure 5.2. Latest year of DHS** (Source: DHS at [www.measuredhs.com](http://www.measuredhs.com))

### *Demographic Surveillance Sites*

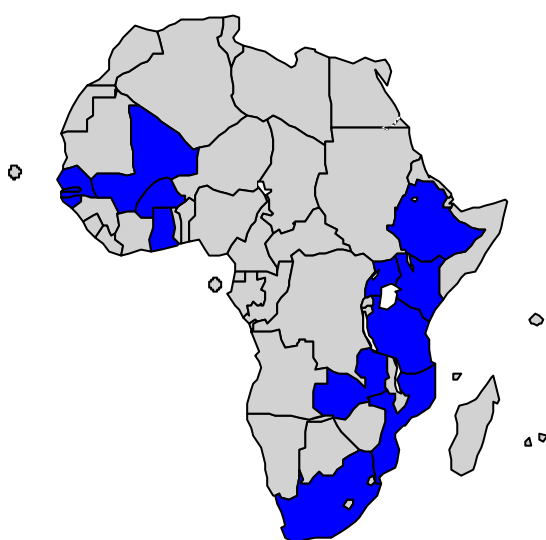
Demographic surveillance sites (DSS) are essentially population clusters which are routinely monitored for vital events. Data from such routine enumeration enable computation of birth and death rates, for instance, for the population under surveillance. Birth and death rates from these communities may not be truly representative of the general population, because in general, a variety of health and welfare measures are created by the donor agency or health and community services are provided by the research institution.

In Tanzania, for example, three complete districts constitute the population under surveillance for which the sole purpose is to monitor mortality. The selection of the three districts had been done in a manner to simulate the socio-economic and geographic distribution of the national population. This makes the data from these sites extremely useful for understanding the national mortality patterns. The Tanzanian Adult Morbidity and Mortality Project has also pioneered the use of full-scale verbal autopsy procedures to ascertain the causes of deaths registered during the surveillance, adding tremendous value to the data. Details of the verbal autopsy methods are discussed later in the report.

Figure 5.3 highlights the location of various DSS sites in Africa. Managers of these individual DSS projects along with research and donor institutions established a network in 1997 called INDEPTH (An International Network of fieldsites with continuous Demographic Evaluation of Populations and Their Health in developing countries) to link the activities being undertaken at these various sites. The INDEPTH network has worked towards setting up standardized methods and procedures, and has recently added verbal autopsy procedures to the data collection strategies in some sites. The populations participating in DSS sites are usually large when compared to samples for national household surveys. The fact that they are almost always from a set of geographically contiguous communities (e.g. a subsection of a district), however, raises serious questions about the extent to which findings from DSS sites can be generalized to national populations. In addition, many sites were established with the expressed intent of conducting intervention research on major diseases. The provision of care and services to these populations may well further affect the ability of DSS sites to

represent the national experience. In such a situation, data from these sites can serve as a reference point regarding the true level of mortality experienced by the population. The local experiences developed in establishing the administrative procedures for surveillance and in training field and statistical personnel in each of the national settings is extremely valuable and should be drawn upon while establishing more extensive and nationally representative registration systems.

**Figure 5.3. INDEPTH sites in Africa** (Sources: UN Population Division. World Population Prospects: the 2002 Revision and INDEPTH Mortality Monograph, [www.indepth-network.net](http://www.indepth-network.net))



Country	Total Population 2002	INDEPTH Fieldsite Population
Burkina Faso	12206430	180000
Ethiopia	66038824	35000
Gambia	1369940	16400
Ghana	20174859	139000
Guinea-Bissau	1255756	101000
Kenya	31903510	55000
Mali	12017740	10000
Mozambique	18985579	35000
Senegal	9907107	18000
South Africa	44201610	146000
Uganda	24778979	12000
United Republic of Tanzania	36818687	470000
Zambia	10870938	10000

### ***Vital Registration Systems***

Statistics based on civil registration of vital events are called vital statistics and the process is commonly termed vital registration. The records produced by the registration process serve a dual function, firstly the legal requirement to establish civil status of individuals, and secondly, to serve as data sources for measuring indicators useful for policy and planning purposes. Civil registration is essentially a function of the government to: 1) establish individual civil status (registration of births, marriages, deaths and other vital events; and, 2) provide data for policy and planning purposes.

Vital statistics on deaths and causes of death drawn from complete civil registration systems is the “gold standard” for mortality statistics. A complete civil registration system is one in which all births and deaths in the population served are legally registered, and for each registered death, there is available a medical opinion on the cause of death. The process of establishing and developing a system is evolutionary, and in many countries has taken over a century for well-functioning civil registration systems to be established. Today, about 80 countries have complete civil registration systems. In about 50 additional countries, it

appears that the systems are in advanced stages of development, in which the population coverage for registration of events is high. The quality of information on causes of death from the systems is doubtful because many deaths occur in the absence of medical attention. The two largest of these countries, China and India, have established SRS (discussed in the next section) which provide sufficient coverage to produce useful national level data, although these systems cannot and should not serve as permanent substitutes for complete civil registration systems.

#### Figure 5.4. Vital Registration Systems – latest available data and coverage rates

(Source: WHO.)

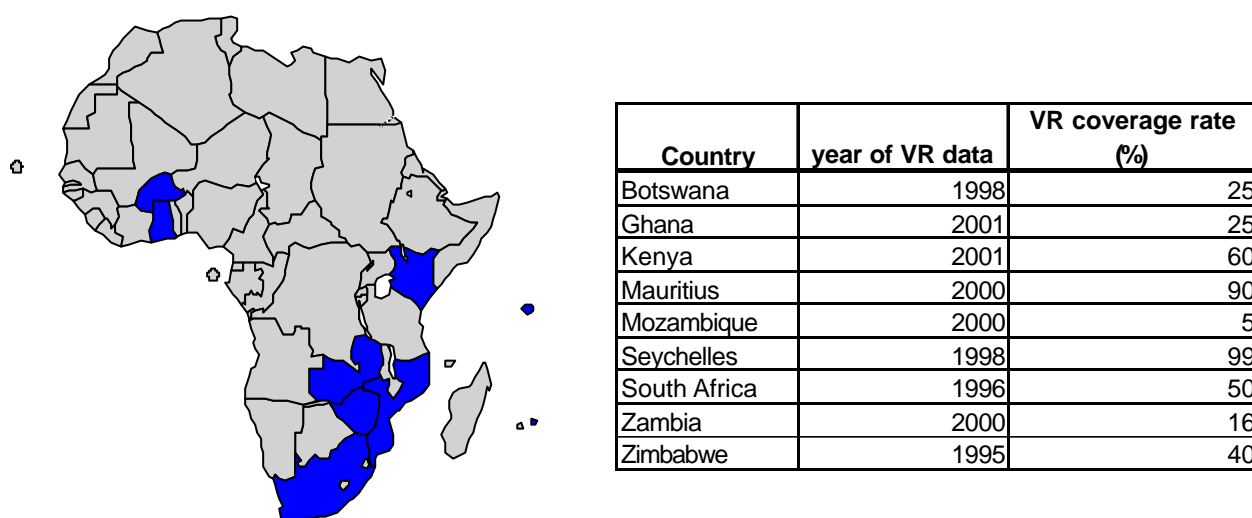


Figure 5.4 shows data availability from vital registration systems in African countries. These data were received at the WHO as part of a data collection exercise for the Global Burden of Disease 2000 project. All Member States were contacted for vital registration data and nine African countries provided data on deaths by age, sex and cause, at the listed coverage rates (Table 5.1 and Figure 5.5). These rates were computed using the WHO life table based figures for estimated deaths at national level as denominators in the computations. Even among these nine countries, the level of data detail varies substantially, particularly in terms of age groupings and use of the International Statistical Classification of Diseases and Related Health Problems (ICD) codes for causes of death. Nevertheless, they served as important local data for estimating national burden of disease and were used as inputs in the various statistical models that are employed for indirect estimations. It is likely that similar data exists in many other Member States within Africa, with varying levels of coverage and completeness. A concerted exploration of the factors that determine data availability was considered necessary to understand the situation, with a view to implement strategies to improve availability of national level statistics.

These factors and barriers contributing to data availability differ from country to country, however, some common features emerged from discussions about national experiences during the workshop. Participants described the vital registration processes in their country

and presented some of the problems and important issues. Prior to the workshop, participants were requested to obtain and share legal documents and forms, a summary of which is provided in Table 5.2. When interpreting these data, it should be understood that complete vital registration demands a well-functioning and harmonious societal, legal and administrative environment within the represented population, and incompleteness needs to be addressed from all these perspectives.

### **5.3 Issues in the implementation and improvement of national death registration systems**

Understanding the multiple benefits, the governments of South Africa and Zimbabwe made significant efforts to improve vital registration data availability. Bradshaw and Schneider's review, "Vital Registration and Statistics in South Africa: Case Study Metropolitan Cape Town", is a seminal publication in this area of work and details the factors examined as well as the methods employed to improve vital registration coverage in South Africa (see Table 5.2). In particular, the factors that determine quality of data from civil registration and vital statistics systems were described and listed as: (a) political will; (b) organizational issues; (c) system design; (d) legal matters; (e) capacity building and quality control; and, (f) public awareness. Participants from each country at the workshop noted similar issues during presentations and the ensuing discussions.

#### ***Political will***

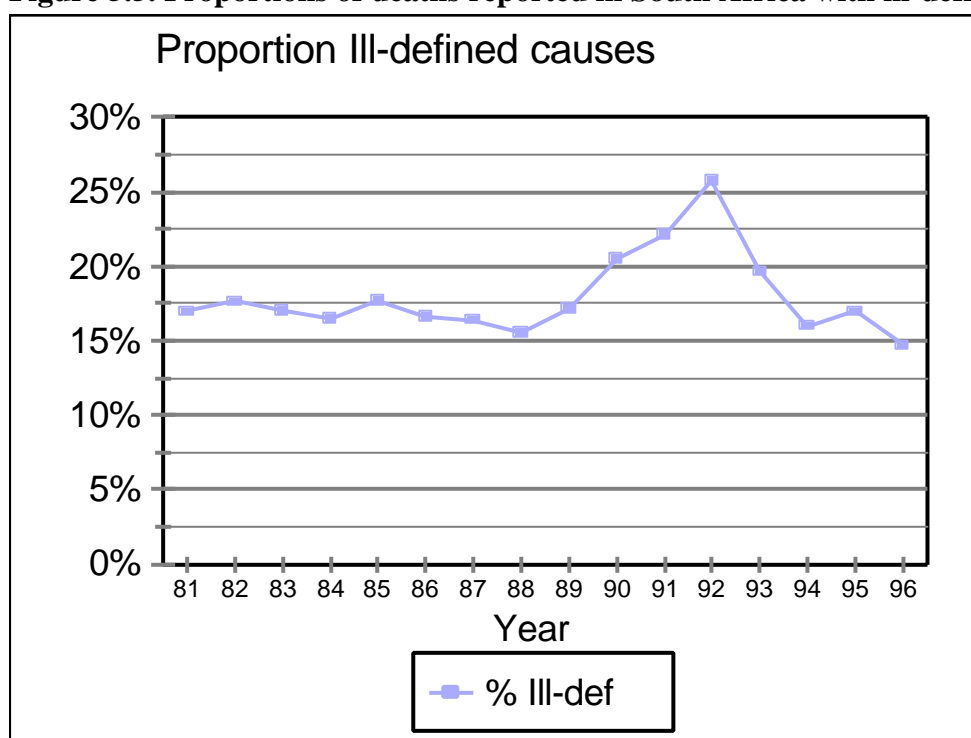
Country representatives stated the necessity for strong political support for implementing a coordinated vital registration system. Notably, the representative from Ethiopia mentioned the political support leading to the enactment of the Civil Registration Laws, which is currently in draft form within the legislative process. Also, the establishment of the Vital Statistics Registration Study team in Ethiopia demonstrates the recent renewed political will towards system development. South Africa has demonstrated the importance of such support from the national and provincial governments. In 1995, a strategy for improving Vital Statistics and Civil Registration was included within the framework of the national Reconstruction and Development Program which propelled the issue into the political realm and resulted in the progress achieved in their vital registration system (see Table 5.1).

While registration is primarily the responsibility of governments, and political support from elected representatives is important, public involvement is also essential. It is possible to improve civil registration systems with relatively small investments in building public awareness and building capacity among government employees responsible for these functions. An understanding of the importance and uses of vital registration within the system and policy makers at national level will also improve accuracy and coverage.

**Table 5.1. Estimated proportion of adult deaths reported**

Year	Number of adult registered	Estimated
1989	141 876	60%
1990	129 256	54%
1991	145 587	59%
1992	152 485	61%
1993	168 489	57%
1994	205 266	73%
1995	231 932	79%
1996	258 220	85%
1997/98	295 483	87%
1998/99	326 761	87%
1999/200 <sup>+</sup>	366 790	89%

Source: Dorrington *et al*, 2001

**Figure 5.5. Proportions of deaths reported in South Africa with ill-defined causes**

Source: Calculated by Bradshaw, D., using data obtained from StatSA

**Table 5.2. Summary of National Vital Registration Laws and Regulations**

<b>Country</b>	<b>First VR laws</b>	<b>Latest update</b>	<b>Nation wide compulsory registration</b>	<b>ICD cause of death certificate</b>	<b>Latest year of statistics</b>	<b>Coverage</b>	<b>ICD codes used for tabulations</b>	<b>Remarks</b>
<b>Botswana</b>	1968	1983	Not specified in act or rules	Yes	1998	26%	ICD 9 BTL	Cause recorded only for health facilities in urban areas
<b>Ethiopia</b>	No specific law. Family Civil code 1960 contains some clauses	Draft laws under legislative process	Current system voluntary, with registration driven by individual interest	Not known	Not available at national level	Unknown	ICD 6 in use for municipal level statistics	Vital statistics registration study team overseeing legislation and implementation
<b>Ghana</b>	1965	1968	1968	Not known	2001	25%		Only hospitals from Eastern region reporting with cause
<b>Kenya</b>	1928	1971	1971	Yes. For home deaths, lay reporting using registration form with 12 broad causes	2001	60%	ICD 10 for hospital stats. No ICD codes in national tabulations.	National level data includes both medically certified and lay reported cause of death information without ICD codes, restricting data usability
<b>Mozambique</b>	1975	1976 and 1988	No law about compulsory national registration	Yes, but only for hospital deaths	Not available at national level	60 % urban, 10 % rural	ICD 7 or 8 used for health unit deaths.	Health unit deaths, both in urban and rural areas have medically certified causes. Some deaths outside health units might as well have medically certified deaths.
<b>Tanzania</b>	1923	1989	Not specified in act or rules	No	Not available at nat'l level	Unknown	Unknown	AMMP data used for health policy and planning
<b>South Africa</b>	1959	Act amended in 1992, form gazetted in 1998	1978	Yes	1996 (complete), 2001 (sample)	78% in 1996	ICD 10 from 1997 onwards	Recommendation to use verbal autopsy methods to assign presumptive cause for deaths registered by village headmen. Relatively high proportion of ill-defined natural causes and undetermined unnatural causes.
<b>Zambia</b>	1898 for whites only	1973	In law but driven by individual interest	Yes	2000	16%, only in urban areas	Non ICD categories used for causes and only two age groups	Multiple laws and agencies for different, legal and administrative framework, needs streamlining
<b>Zimbabwe</b>	1986	1994	1986	Yes	1995	40%	ICD 9 3 character	Recent coverage improvements in VR coverage, employing mobile free registration drives

### ***Organizational issues***

In almost all countries, multiple organizations are involved in the overall process of vital registration, with varying responsibilities. In general, civil registration is the responsibility of the Ministry of Home Affairs in most countries. Other agencies are typically involved, such as Central Statistical Services to process data and the Ministry of Health to coordinate coding of health information (cause of death) and to produce information on selected demographic and health indicators at the national level. The structure of systems differ by country, for instance, in Ghana, responsibilities have shifted from the Ministry of Local Government in 1966, to the Ministry of Finance in 1972, to the current Directorate of National Statistics in 1981. Such shifts delay development and functioning of the system. Currently, while overall coverage of death registration from all regions is about 25 % in Ghana, information on causes of death is available only from hospitals in the Eastern region. Similarly, in Zambia, multiple agencies with overlapping responsibilities impede the development of an efficient system. In Botswana, published causes of death statistics seem to include only health facility deaths, largely from urban populations. Lack of intersectoral collaboration was mentioned as a serious impediment to efficient data collection in Kenya, which has a relatively strong infrastructure in place for information collection at peripheral levels.

Data quality is problematic at local levels, where untrained village assistant chiefs in Kenya and village headman in South Africa register deaths. It was felt that training and a notifier system, using health workers, midwives and school teachers, could increase registration as well as improve quality of cause of death information.

In summary, a need for strong central direction, supervision, and coordination of separate elements within the vital statistics system is a requirement. A useful exercise would be to create a flow diagram of the data collection process, with a set of notes clearly defining levels and responsibilities, both within and across agencies. It was recommended to establish a Central Advisory Committee, with members from all responsible agencies (e.g., Home Affairs, Statistics and Health) to oversee the functioning of the system, and to localize problems with effective early solutions. When modifying or restructuring the vital registration system, it was recommended to bring together data users and the data producers, to ensure that the final outputs are satisfactory for the purposes for which they are collected. Adequate training of key contributors to data quality (such as physicians certifying causes of death and ICD coders) is part of improving the outcomes of any system.

### ***System design***

Unit record data collection is an integral element of civil registration systems, largely from the legal purview of maintaining and providing individual level records. It also provides a vast amount of data valued for socio-epidemiological research. However, comparability of data across populations and over time demand standard data definitions and collection processes embodied in the design of forms, coding systems and summary tabulations. While a certain degree of variation is unavoidable, some basic elements must be incorporated into standard formats, not only for quality and comparability, but also for convenience in data management and interpretation. Still births are a common problem where clear definitions and guidelines regarding registration should be provided.

In South Africa, a new form has been introduced that permits the functions of registration and collection of health information in one form. At the same time, separation of cause

of death information from the rest of the form is recommended as a measure to maintain greater confidentiality of these data. It would also provide certifying physicians more freedom to express their professional opinion about the presumptive cause of death.

In Tanzania, the form for reporting death does not conform to the design prescribed in the WHO international form of medical certificate of cause of death. In Kenya, the form used by assistant village chiefs to register deaths contains a list of twelve causes, one of which has to be selected by the registrar as the underlying cause of death. Use of dissimilar formats in urban and rural areas leads to difficulties in data compilation and comparability. In Botswana, Zambia and Zimbabwe, the WHO cause of death certification format is used for deaths certified by medical practitioners, but it is not known how information on cause of death is collected for deaths registered from rural areas. In Mozambique, cause of death data have been compiled from death registers in urban areas, and it is not known how cause of death information is provided for entry into the register.

All these issues call for attention to standardize forms, the elementary tool in data collection, as this will enhance data comparability within and across nations. There was also a recommendation for some basic definitions and procedures to be provided on the reverse side of each form, to act as ready reference for personnel entrusted with responsibilities for completing the forms. Such instructions have been incorporated into the proposed two page design of the death certificate in South Africa.

Other important issues in system design include data standards and publication of statistics. One of the key elements in reporting data on cause specific mortality is the use of ICD codes. Standard practices demand that underlying causes of death need to be coded according to current version of the ICD. The latest version available is the Tenth Revision (1993), and it is recommended that national level statistics should be tabulated at the ICD 10 three-character level. Also, tabulations should comprise standard age groups, for both infant deaths and deaths at older ages. The ICD instructions volume prescribes tabulation at various different age groupings, depending on level of detail of available data, but it is advisable to use standard five year age groups up to age 85 and above.

While many countries are in the process of transitioning from ICD 9 to ICD 10, there are still some countries, Zambia, Kenya and Mozambique, that publish statistics using only disease labels without corresponding codes. This limits both the understanding and the usability of the data. Ethiopia uses ICD 6. The coding process in Zimbabwe is hampered from insufficient technical and human resources, so much so that data from 1996 to 2002 remain in storage in hard-copy awaiting coding and computerization. In South Africa, statistical tabulations are available only up to 1996. In general, a time lag of up to two years is considered reasonable, considering the need to collect, collate, validate and then publish cause of death statistics.

Developing electronic data standards and use of data interchange formats can help in speedy processing of large volumes of data. Lack of data standards and use of dissimilar data formats in Kenya were mentioned as major system design problem.

### ***Legal framework***

A comprehensive legal framework is fundamental to the establishment of a well-functioning civil registration system. The legal framework should contain a Registration Act, adopted by the legislature, and in practice also include Rules and Regulations (based on the legal act) that are issued by the Executive arm of the government. Legal frameworks will obviously vary by country, but overall, the Act and the Rules should provide, among other relevant details, the following:

- simple and unambiguous definitions of the vital events under consideration;
- adequate definition of duties and responsibilities of the citizen as well as the government (or concerned representative of the government);
- comprehensive set of forms and instructions on use of the forms that enable registration (establishment of civil status) and data collection (policy and planning);
- clear administrative hierarchy for the collection and submission of data;
- nomination of responsible individuals at each level in the hierarchy, with adequate delineation of responsibilities where necessary;
- description of essential duties and responsibilities of appointed governmental functionaries at each level, for ensuring compliance with provision of civil registration facilities to citizens, as well as for smooth and systematic processing of data in central administration;
- responsibilities of central agencies for collation, analysis, and publication of vital statistics;
- provisions for public access to individual records, within relevant legal boundaries; and
- other relevant details as necessary for local and governmental purposes.

The existence of a comprehensive and up-to-date legal framework is the fundamental basis for establishing or improving a complete civil registration system. Comprehensive refers to fulfilling the above essential requirements, and 'up-to-date' refers to use of latest data standards (for example, ICD 10) to conform to international norms for such data collection. The summary of legal frameworks in Table 5.2 indicates the need for review in some of the countries. Also, the evolutionary nature of the process can be seen from the fact that extension of registration to cover all regions or all communities within some countries has taken nearly half a century. Zimbabwe has taken a positive step by introducing the vital registration system to cover the entire country from its inception in 1986 and has made rapid progress towards establishing a comprehensive system. Moving from ICD 9 to ICD 10 coding and decreased lag-time in data availability would ensure that it is also up-to-date.

At the national level, reviewing the legal framework and addressing problem areas are important first steps for improving the civil registration system and incorporating latest data standards, data requirements, human rights and civil status issues. These steps demonstrate political will and transmits the right signals on this issue. South Africa amended the Births and Deaths Registration Act in 1992, with detailed provisions for registration and notification of births and deaths, which was gazetted and updated in 1998 to legislate the new form. This act superseded a number of previous acts, all of which had only broad provisions for collection of vital and health related statistics (Statistics Act 1976, Health Act 1977 and National Policy for Health Act 1990).

### ***Capacity building and quality control***

The need for training in various aspects of the complex process of vital registration was expressed repeatedly by all workshop participants. Capacity building is required for data collection, local and central data transferring and processing, and data analysis and dissemination.

New or revised data collection systems require training inputs for peripheral functionaries, both administrative (local registrars) and technical (statistical assistants).

The quality of cause of death information was a concern for all countries. South Africa has adopted ICD 10, and has implemented a number of methods to improve data quality.

To start, death certification and ICD code manuals were distributed to hospitals, academic and health professionals. Letters were despatched to all registered doctors, informing them of the revised procedures for death certification and relevant guidelines.

Provincial task teams were set up to oversee the implementation of the revised procedures, and sample of 16,000 forms were evaluated, the results of which were used to provide feedback to provinces. The current version of the ICD manuals provide a basic description of the ICD together with practical instructions for cause of death certification and mortality and morbidity coding.

These measures are good examples of the various methods that can be employed to improve data quality, and multiple methods will have to be adopted, considering the complexity of the process. In rural areas, a move has been initiated to allow village headmen to register deaths, and to employ verbal autopsy procedures to assign presumptive cause of death, with the help of community health workers. Simple training programs using locally available resources (for example, hospital case records and completed cause of death certificates providing correct and incorrect examples) can be drawn up and conducted periodically, to introduce and maintain high quality standards.

Amendments to medical curricula (both graduate and post graduate) to include training about the legislation pertaining to vital registration and notification, as well as the technical aspects of cause of death certification, are essential steps towards improving data quality. The role of feedback to physicians, as used in South Africa, has the potential to be a strong influence in improving data quality. In rural areas, capacity building is required among registrars, clerks, statistical assistants and other related personnel, to implement all new or revised aspects of the civil registration system. In Kenya, lack of training and feedback has been mentioned as a cause of apathy and lack of motivation in staff. Non-utilization of data at local levels combined with a lack of capacity has also been cited as a cause of inattention to the system in Kenya.

At more central levels, training is required for personnel involved in data transfer, processing, analysis, tabulations, data validation and dissemination. The Kenyan participant believed that judicious use of computers, with proper training, can vastly improve data processing and analysis.

Other useful quality control measures cited by South Africa are the use of data from the population census and sample surveys to measure the completeness of registration. A clear need has been expressed to test the reliability of data from registration, and not to follow 'uncritical acceptance' of mortality data.

Cause-specific mortality statistics available at national level should be reviewed according to specific criteria (Mahapatra and Rao, 2001). These criteria include

administrative criteria such as coverage and completeness, applicability for sub-national analysis, timeliness of publication, as well as specific technical criteria such as proportion of unclassifiable deaths; misclassification by age, sex and cause; consistency of cause specific mortality proportion with general mortality and over time; and an evaluation of the content validity of the reporting system. This calls for a description of the process of data collection, proportion of causes medically certified and mechanisms for lay reporting. Such evaluation of cause specific mortality data is critical for a clear understanding of data quality, before further utilization for monitoring, health policy, and planning.

### ***Public Awareness***

Active public participation is essential in the process of civil registration. All participant Member States expressed a need to create stronger public awareness of the basic purposes of civil registration and citizen responsibilities. Impressing the importance of civil status and reporting births, deaths and marriages on citizens can be indicated by linking availability of individual vital records to basic citizen's rights. For example, in some countries, school enrolment is conducted based on proof of date of birth from birth certificates. Another mechanism can be the inheritance laws and survivors and dependency benefits linked to availability of valid death records. Vital records are hence can be used to ensure respect for human rights. However, in many countries, the average person would be unaware of these relationships, so public cooperation needs to be actively solicited. The State has an obligation to have the necessary organizational structure, sound legal framework, and adequately trained staff to provide these services.

Mobile registration units in Zimbabwe have been used to provide free services for birth and death registration while waiving certain penalties for late registration that would have been enforced under normal circumstances. In South Africa, an unofficial notifier system involving midwives, nurses, graveyard attendants, schoolteachers and religious officials has increased community participation through increasing awareness while enabling people to become part of the registration process. Such drives have enhanced the levels of registration and have served the additional purpose of increasing public awareness. In many countries, mass media campaigns including newspapers, radio and television are used to promote public awareness of the citizens' rights and responsibilities towards civil registration of births and deaths.

### ***Practical Classification***

The categorization of problem issues and barriers to establishing civil registration systems is useful to understand the situation in any given national setting. However, when it comes to actually tackling these issues, availability of resources plays an important role in setting priorities for action. In this regard, the problem issues can also be categorized according to the following classification (as described by Powell in, Linder and Moriyama, 1985):

1. Relatively intractable problems: such as illiteracy, widely dispersed populations, lack of adequate infrastructure to provide services, and so on. Such problems can be resolved mainly through long-term social and economic development. Sometimes, a deeply embedded socio-cultural pattern such as suspicion of official enumeration can also hinder civil registration systems.
2. Solvable problems, which require large amounts of funding. Adequately trained staff, office space, record storage/retrieval facilities, essential forms and supplies etc are issues that have large capital and running costs, which may be substantial enough

to deter the attempt to set up a comprehensive vital registration system. In such cases, it may be worthwhile to consider establishing sample registration units, essentially for the purpose of generating vital statistics useful for policy and planning.

3. Solvable problems, with small financial inputs. Adequate legislation, procedural problems that can be solved by planned intersectoral collaboration, specific training needs to improve certain weak elements in the system etc fall into this category. It is speculated that many problems within the South African system would fall into this category.

An analysis of national level problems along these two types of classification would help setting priorities towards the speedy establishment of viable civil registration systems, and it is recommended that Member States undertake such critical reviews of existing systems, and make necessary choices.

It is difficult to plan a comprehensive and complete civil registration system at national level, from both the financial and management perspectives. In such situations, it would be useful to consider the option of setting up DSS or SRS, and using verbal autopsy methods to get information on causes of death, as discussed in the following section.

#### **5.4 Sample Registration Systems (SRS)**

Sample registration systems are useful interim measures towards developing complete civil registration systems. They are essentially designed to produce vital statistics for national or sub-national policy and planning. While they can never substitute for a proper civil registration systems, since they do not fulfil the State's obligation to provide civil registration services to citizens, they can be used as pilot ventures towards the establishment of complete systems, by gradually extending sampled areas as more resources are available. By this, the usually long lead time involved in establishing complete systems can be reduced, during which time representative vital statistics at population level will be produced. In summary, SRS are efficient, economical, and speedy to establish, all three of which are necessary conditions in developing country situations.

During the workshop, a brief outline of the attributes of SRS were described, and then illustrated using the examples of functioning systems in India and China. The approach of using sampling appealed conceptually to workshop participants, and generated much discussion on the practical applicability in different country situations. The following is a synopsis of the discussions, highlighting specific around the scope and benefits of sampling, technical details, and certain limitations.

##### ***Scope and benefits of sampling***

As described earlier, sample systems are basically self-sufficient vital statistics systems, in which there is continuous enumeration of births and deaths within a selected population, and this population is enumerated periodically, as necessary or feasible. The scope of sampling extends from sampling to represent the complete national population, or may be restricted to sub national regions that may be underserved by civil registration. Also, sampling may be used in conjunction or as a supplement to fully functioning vital registration systems, for (a) evaluation of statistics, (b) as experimental areas for testing system modification, (c) to allow collection of data on additional variables / to permit more detailed analyses of some variables.

The choice of sampling strategy would depend on existing country situation. For example, in Kenya, which has a reasonably strong civil registration data collection system, a selected number of sample units could be established to test the completeness of civil registration. In South Africa, where the urban registration is near complete, sample areas in rural areas may be a useful supplementary source of data for compilation of national statistics. In Tanzania, four major districts are covered by complete registration under the AMMP, so it may be useful to have sample units in other districts to get national data. In most countries, however, it would be better to start with establishing nationally representative sample units, and build up from there.

The key benefits of SRS are that they are less formidable to set up and maintain (at greatly reduced costs) and produce high quality, up to data statistics from the start. Also, they can serve as primary units, which can be expanded towards complete registration. In both India (the Sample Registration System -SRS) and China (the Disease Surveillance Point System – DSP), these systems have been developed to produce nationally representative statistics, since it is inconceivable to establish complete civil registration systems to cover the entire population. However, in India, the SRS has fuelled the development of the civil registration system, which currently registers around 50% of births and 40% of deaths at the national level, with some achieving nearly 75 % of completeness of registration. Having said this, there is still much to be achieved in terms of data quality, especially in terms of information on causes of death. In China, another system titled National Mortality Statistics system was earlier established to cover larger populations, and currently achieves 80 % coverage of death registration, but is mainly concentrated in the Eastern half of the country. Hence, the need for the DSP to obtain national representation.

### ***Technical aspects of sampling and registration***

Representative sampling requires choices to be made regarding the level of stratification that is desired, or can be achieved within available resources. Stratification could be based on environment, ethnic sub groups, socio economic status, rates of population growth, or any other important issue at national level that demands separate consideration and analysis. Statistical methods for sampling include area probability sampling, and probability proportionate to size sampling, and are issues that are readily dealt with by trained statisticians, as long as appropriate sampling frames are available.

In India, a multistage stratified random sampling plan was implemented, using state, urbanization and population size as the strata. About 6700 sample units are in operation, covering a total population of little over 6 million. Sample sizes are representative for compilation and publication of fertility rates, and age sex specific death rates at state level, for urban and rural populations separately.

In China, a multi-stage random sampling strategy is adopted, using a mix of socio-economic indicators such as population density, dependency ratios, employment patterns, etc. As can be seen, selection of strata is a local choice. The system is in operation in 145 sites, covering a total population of 8.7 million. Results are published by age, sex and cause for five socio economic population strata (one urban and four rural).

Operational details of the Indian system are as follows:

- From the decennial census sampling frame, a set of sample units are selected, based on the sampling strategy

- In each selected sample unit, a baseline survey is conducted, to build up the household register, along with a notional street map with buildings etc
- A local resident serves as a continuous enumerator, recording births and deaths, while updating the household register. In most instances, the village primary school teacher / post office clerk etc function as the local enumerators, and receive an additional salary for this service
- Once every six months, a regular staff member from the SRS, called the supervisor, visits the units under his / her jurisdiction, and conducts an independent complete household enumeration, with an independent register, and records vital events occurred over the previous six months
- Lists of events from local enumerator and supervisor are matched, and unmatched events are reconciled by field verification, to obtain a complete list of events
- Data is collected periodically from all units, and fertility and mortality rates at state level for urban and rural areas are published annually.
- The latest complete annual report available is for the year 2000, and draft estimates are available for 2001
- The new sample of units from the 2001 Census has been selected, and will become operational in 2004.
- In the new sample, verbal autopsy methods are being added, in an attempt to obtain nationally representative cause specific mortality structure. The verbal autopsy interviews will be conducted by the SRS supervisors during half yearly visits

In China, a similar system is followed, except that the information on cause of death is more reliable, by use of available hospital record / medical opinion on cause of death based on verbal autopsy procedures, described below

### ***Limitations of sampling***

The principal limitation of sample registration is that it does not fulfil the legal obligation of the State to provide registration services. In addition, though there is overall cost reduction, there are higher costs per unit to achieve high data quality, especially in terms of training. All administrative, technical and statistical problems faced in complete registration also exist in sampled units. Also, small sample sizes result in estimates of vital rates that are strong at national or state level, but not at local levels.

### ***Verbal Autopsy***

A verbal autopsy is an interview of relatives of the deceased to gather information about the symptoms and events that preceded the death, in an attempt to ascertain the cause of death. In areas where there is little or no medical attention at the time of death, such methods are the only way to collect information on causes of death. In these circumstances, there are two basic assumptions that underlie the principle of verbal autopsy:

1. The symptoms, signs and events for individual causes are unique and clearly distinguishable from those of other causes
2. Relatives are able to recall specific details about the illness / events preceding death

Verbal autopsy methods have been found useful for identifying causes of infant deaths, as also deaths due to maternal causes and injuries. However, causes of adult deaths are difficult to identify, as deaths caused by some important causes have overlapping symptom complexes. Such situations lead to significantly large proportions of deaths

being classified as ill defined, or only symptom based causes of death, which are not very informative.

In some developing countries, health facilities and services are available or accessible in rural areas. Also, individuals with chronic diseases may have visited a health facility in nearby town or urban areas. In such situations, there is some likelihood of members of the household possessing some information regarding the illness before death. To gather such information, questionnaires have been developed to include these items, as well as an open narrative section to record all information known to the respondent in the form of a story.

The AMMP in Tanzania have pioneered the development and implementation of such verbal autopsy questionnaires in their field areas, and have reported better defined cause of death patterns. Three separate questionnaires are used, one for neonatal deaths, one for child deaths between 1 month and 5 years, and one for deaths at all ages above five years. A detailed description of their methods and results is available, as also the forms and instruction manuals. The AMMP methods have been used as starting points for revising verbal autopsy procedures in China and India, and are currently being tested for local adaptation in Turkey, Egypt and some other countries. The reliability and validity of information obtained by these methods is being tested in large-scale validation studies that are underway in Tanzania and China. The WHS includes a mortality module, in which verbal autopsy methods are being used to ascertain causes of death among children and adults in the surveyed population. Separate verbal autopsy questions are used for child deaths identified in the Birth History section, and for adult deaths identified from the sibling survival history from the respondent. The survey will provide percentage probabilities of positive and negative responses to each question in the population under study.

A major challenge lies in using this information to understand levels of mortality due to individual causes in the survey population. One way to achieve this would be to administer exactly the same questionnaire in a set of deaths where the true cause of death is known, and measure the percentage probability of positive and negative responses. The process of such data collection is referred to as a validation study.

Bayesian methods can then be applied to combine the information from the WHS (population level), and the validation study (selected deaths), to predict a cause specific mortality distribution in the population under survey. WHO is currently seeking expressions of interest to carry out such validation studies in a range of countries.

The adult causes of death which the WHS module intends to identify are injuries, maternal causes, ischaemic heart disease, cerebrovascular disease, tuberculosis and HIV/AIDS. The relevant questions are shown below in Table 5.3.

**Table 5.3 Verbal autopsy questions on Adult Deaths in the World Health Survey**

Age :	Sex :	
1.		If deceased, a woman aged 15-49, was she pregnant when she died ? Yes / No
2.		If deceased, a woman aged 15-49 did she die during childbirth? Yes / No
3.		If deceased, a woman aged 15-49 did she die within 2 months after the end of pregnancy or childbirth? Yes / No
4.		Was the death associated with injury? Yes / No
5.		Was it due to
		Accident 1
		Suicide 2
		Murder 3
		War 4
		Natural disaster 5
6.		Provide details of events that led to the injury. What was the mechanism or cause of injury?
		Motor vehicle 1
		Pedestrian-vehicle crash 2
		Motorcycle 3
		Pedal cycle 4
		Fall 5
		Gunshot, firearm related 6
		Landmine / bomblast 7
		Stab / cut / pierce 8
		Fire / burn 9
		Poisoning 10
		Near drowning / drowning / submersion 11
		Other mechanism / cause of injury 12
7.		Where did the injury occur?
		Home 1
		School 2
		Street/highway 3
		Parking lot 4
		Trade and service areas (shop, bank, etc.) 5
		Farm 6
		River/lake/stream/ocean 7
		Industrial/construction area 8
		Other public building 9
		Other 10
		Specify others 11
8.		Did the deceased report / experience chest pain lasting less than 24 hrs in the month preceding the death? Yes / No
9.		Did the deceased experience paralysis of any part of the body in the month preceding death? Yes / No
10.		If yes, was the paralysis accompanied or followed by sudden loss of consciousness? Yes / No
11.		Did the deceased have a cough that lasted more than 3 weeks? Yes / No
12.		If yes, was there blood in the sputum ? Yes / No
13.		Did (s)he receive any medical treatment for tuberculosis ? Yes / No
14.		Did the deceased have diarrhoea that lasted more than a month ? Yes / No
15.		Was there any rapid loss of weight ? Yes / No
16.		Were there any white patches in the mouth ? Yes / No

### **5.5 Recommendations for improving death registration systems**

In conclusion, there was a felt need for sound local data on age, sex and cause specific mortality, to be used as inputs for measuring population health status, and informing health policy. It was also agreed that civil registration systems are the best source of such data, and need to be strengthened to serve as routine systems to provide such data on a regular basis, as well as to meet the government's obligation to provide these basic civil services.

Participants expressed the necessity and desire for discussion about the various 'nitty-gritty' issues surrounding civil registration to bring out the problems within the system.

These discussions can further stimulate action to resolve them. It was also expressed that international workshops on this theme would help in two ways, firstly in understanding that problems within national civil registration systems are universal (which is reassuring, considering the enormity of the task ahead) and secondly, that sharing experiences provides information about the methods and strategies to resolve these problems. In particular, the participants expressed the following specific recommendations:

1. Country level expert teams (like the team in South Africa) should be established to critically review national civil registration systems in specific areas, namely legal frameworks, organizational issues, system design, training needs and quality control issues, methods for raising public awareness, and levels of political will to improve systems.
2. Key problems identified from above analysis should be further categorized according to Powell's classification (based on required financial inputs and feasibility), and priorities should be set for intervention, with specific targets to monitor progress.
3. Low cost public awareness programs and training for peripheral data collection on vital events should be implemented independent of the review process, and as early as possible.
4. Similarly, building awareness among physicians on the importance of mortality statistics, and training of physicians in cause of death certification and coding, should be given more importance in medical education curricula.
5. The country level expert team should also examine the possibility of setting up sample registration systems as interim measures to obtain data for policy and planning. A detailed advisory strategy document on this aspect should be specified among the principal outputs of this committee.
6. Universities with public health, anthropology and social sciences departments should be encouraged to undertake specific areas of research on verbal autopsy procedures, with a view to incorporating such methods within the framework of sample / civil registration systems, as necessary.
7. Capacity should also be developed in disciplines such as demography, epidemiology and biostatistics, to conduct regular analysis of data collected by the registration systems.
8. Regular feedback should be provided by governments in the form of timely annual reports, to monitor the progress in development of registration systems, and as information for health policy.
9. The WHO African Regional Office should provide guidance, technical support and work through country offices and national governments towards achieving the above recommendations. Specifically, proposals for funding towards capacity building and

research should be supported by WHO AFRO, and WHO HQ, in terms of coordination and technical support respectively.

10. The WHO-AFRO office should conduct such international review meetings from time to time, to increase awareness of importance of civil registration, and to monitor progress. Also, AFRO should include review of civil registration/ mortality and causes of death statistics at national level as an agenda item, wherever possible, during various inter country consultations organized annually.

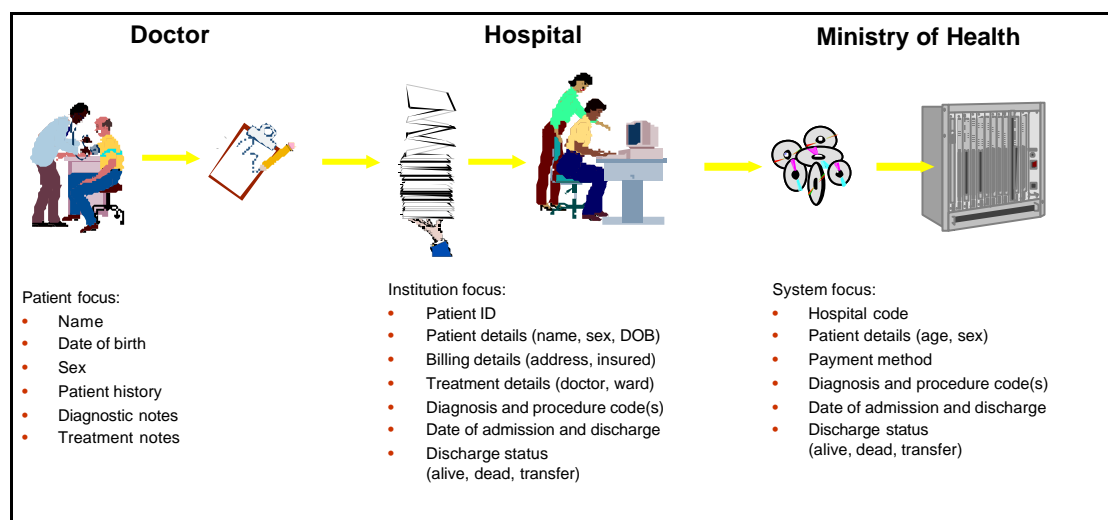
## 6. Hospital Data

Data on hospital admissions provide an important set of information for older people. While hospital admissions and procedures do not reflect the health status of the older population (not all people with a given condition end up in the hospital), hospital data are very useful for the following purposes:

1. estimating the incidence of certain specified health problems (where there is adequate access of the population to hospital facilities);
2. providing information on in-hospital deaths;
3. analysis of health systems performance (including access and coverage of interventions); and
4. Providing diagnostic information, procedure information, discharge status, length of stay, patient demographics, to assist in health service planning, delivery and management.

Barriers to recording and retaining hospital data include, (1) lack of ways to record electronically, (2) lack of resources or expertise to code for clinical information (i.e. ICD codes), and (3) no system for centrally collecting and checking institutional data (see Figure 6.1).

**Figure 6.1. Recognising different reasons for collecting information**



Workshop participants presented overviews of hospital data collections for Tanzania, Kenya, Ethiopia, Botswana, Ghana and Zimbabwe. There are annual publications in Tanzania, Kenya, Zimbabwe, Ghana, Ethiopia, Botswana. Zimbabwe also has quarterly statistical reports. In Ethiopia, Kenya, Zimbabwe, Ghana and Botswana data is collected only for public and missionary hospitals.

Diagnoses are coded using ICD-10 except for Ethiopia (ICD6), Botswana (ICD9), and Zimbabwe, (ICD9). Zimbabwe and Tanzania collate data at district level. Only a restricted number of reports (1000) are produced in Zimbabwe.

### ***Recommendations for data collection in hospitals***

The most desirable scenario would be to have information about inpatient activity from all institutions offering general acute, subacute, or extended acute care inpatient facilities within identified catchment populations. Hospital data is much more useful for analyses relating to population morbidity or health system access and coverage if it is known what the catchment population for a dataset is. Rarely, however, are all hospitals captured by national or sub-national collection systems. From experience, the following categories are more likely to be excluded:

- Military hospitals
- Private hospitals
- Institutions offering nursing facilities only
- Non-hospital based emergency facilities (including “Flying squads”, mobile units in some developing countries etc).

In addition to these exclusions, the usefulness of inpatient datasets for analysis of the health of older people is undermined by imprecise information regarding the catchment populations to which they relate (i.e. the denominator). Developing strategies for minimising uncertainty surrounding coverage is important to maximising the usefulness of hospital datasets.

Outpatient health facilities provided by a hospital are not regarded as part of that hospital’s inpatient load. With the trend towards same-day procedures in some countries, this category is likely to become increasingly important in the analysis of procedural information.

Emergency medical care activity is generally not captured by inpatient data collection systems unless a patient is severe enough to be subsequently admitted and is flagged in the inpatient system as having arrived through the emergency department. Where a separate system is in place, experience has shown that data quality is likely to be an issue. Emergency department collection systems have been useful for determining non-severe injuries in the older population.

Basic information for assessing the usefulness of hospital patient data are the following:

1. Estimated population coverage (e.g. region, population numbers by age and sex)
2. Institutions included (e.g. type, number, size distribution/bed capacity and extent of medical diagnosis)
3. Patient episodes included (e.g. medical diagnosis and/or procedure, rehabilitation, palliation etc)
4. Coding standards (e.g. extent to which ICD diagnosis and procedure coding standards have been applied or ability to provide a diagnostic/procedural coding dictionary where non-standard classifications have been used)

For the development of a unit record database for hospital patients, a limited number of specific data items are of high priority to include in the database. Table 6.1 summarizes the core and expanded data needed for a minimum dataset.

**Table 6.1. Summary of Core Hospital Data for a Minimum Data Set.**

A potential minimum dataset should include at least:	Additional desirable information would include:
1. <i>Year of collection</i>	1. <i>Secondary and subsequent diagnoses</i>
2. <i>Hospital category</i>	2. <i>Secondary and subsequent procedures</i>
3. <i>Age (in single years)</i>	3. <i>Date of admission and separation</i>
4. <i>Sex</i>	4. <i>Unique patient ID</i>
5. <i>Primary diagnosis</i>	5. <i>Intention to re-admit flag</i>
6. <i>Primary procedure</i>	6. <i>Length of stay</i>
7. <i>External cause (for injury admissions)</i>	
8. <i>Discharge status (Alive, dead, transfer)</i>	

## 7. Discussion and conclusions

### 7.1 Discussion of future directions

The summary of the discussions about the MDS Project is included in Section 3 above. The workshop participants discussed lessons learned from the MDS Version 1.0 and potential future directions for the MDS project. Among issues discussed were the finalization of the MDS Version 1.0, the possible creation of an MDS Project Advisory Group, development of a dissemination and use strategy for countries, and the establishment of a process for review and update of the MDS and indicators – including linking to more mainstream efforts to improve health and development.

The country teams involved in creating MDS Version 1.0 expressed wishes to:

- 1) expand collaboration within country, including efforts to involve additional colleagues (particularly experts and specialists). The *ad hoc* nature of the work, would emphasize the need to be strategic in the compilation of the core group and occasional contributors. Key decision and policy makers would need to be regularly briefed about issues/progress and then included at specific times;
- 2) develop work plans that include timelines, coordination, budgets, technical support, and training opportunities in research methods, data analysis, interpretation and use;
- 3) receive training in data harmonization and comparability issues, particularly as related to global priorities; and,
- 4) create thematic seminars on the key issues with corresponding materials.

The efforts to compile MDS Version 1.0 identified major data gaps relating to comparable health status and mortality information for older adults. The World Health Survey provides a major opportunity to address both of these gaps, as does potential collaboration with groups such as INDEPTH. Other strategies were discussed for the measurement of older adult mortality, including strengthening of existing, but poorly operating, vital registration systems and the implementation of low-cost sample vital registration systems and the use of survey instruments such as the sibling survival module in the WHS. A major objective is also to strengthen national health information systems and involve local agencies, including WHO country and regional offices and NGOs.

The MDS Version 1.0 has identified major limitations in the extraction of datasets for the construction of cross-population comparable indicators. This involves not only the clear identification of quantities of interest, and relevant data sources, but the development and documentation of methods for the estimation of indicators for

quantities of interest, using standard definitions and analysis categories. To address this, there is a need to start an indicator review process, including data criteria and standards for MDS indicators. WHO would be in a position to provide technical support for these activities through initiatives such as the Health Metrics Network.

## **7.2 The World Health Survey and related activities**

An important output will be data collected from the World Health Survey and working with data from INDEPTH fieldsites. An oversample of respondents aged 50+ years has been added to Ghana, South Africa and Zimbabwe in the 2002/03 round. In addition to the oversample, plans for longitudinal follow-up of these respondents have been created. This will provide additional change and trend data not currently available.

The WHS will provide health and health-related data on older persons and will be used as a platform for longitudinal study of this population. Three countries, Ghana, South Africa and Zimbabwe, will be included in annual longitudinal follow-up for at least two rounds, providing much needed data on changes, trends and patterns in health status.

This will enhance the value of the current WHS in several ways. Firstly, the sampling design for the main survey will yield a limited number of older adults, so additional oversample of older adults in the longitudinal will dramatically increase the amount of information that will be collected for the study of aging populations. The development and administration of an aging module will also ensure that a wide variety of different types of data relevant to older adults will be available for analysis. Secondly, the addition of a longitudinal component to the current plans for the WHS will enable the assessment of health changes over time on an individual basis and direct linkages between non-fatal health experiences and mortality in settings where these types of data are limited.

Of particular value will be the collection of longitudinal data on aging populations in developing countries using standardized instruments designed to enhance cross-population comparability. Thirdly, this proposal calls for rigorous efforts to cross-validate the anchoring vignette strategy to establish the utility of this approach in the study of changing norms and expectations for health over the life course and the adjustment of self-reported health data to comparable scales. The World Health Survey program provides a flexible platform for collection of reliable, valid and comparable data on the health of populations. This proposed project will take full advantage of this platform to provide opportunities for both focused and dynamic study of the health of older adults, and methodological advances in survey development and analysis geared towards enhancing comparisons across individuals and populations.

## **7.3 Improving national mortality data**

The workshop identified the following priorities and strategies for improving national mortality data:

1. Develop proposals to assist countries in their efforts to create/improve appropriate data collection systems.
2. Identify sources of both financial and technical support for countries (including funding proposal templates, grant writing support and technical support group).
3. Review Verbal Autopsy instruments and methods.
4. Encourage interested colleagues to develop proposals for Sample Registration Systems as an interim step to improve the quantity and quality of mortality data.
5. Develop training workshops and plan for technical support

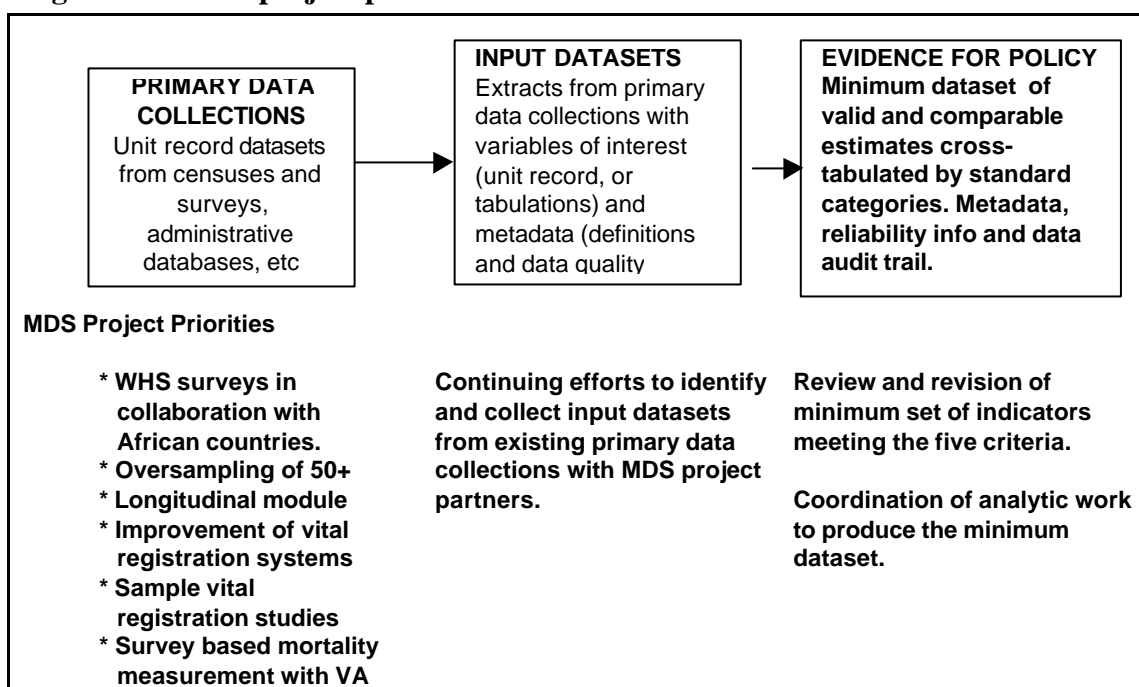
6. WHO to explore standard VA instrument as means to improve death registration data collection particularly in rural areas where physician/health care system capacity to certify deaths is low.

#### 7.4 Conclusions

In terms of the data collection to evidence for health policy cycle (Figure 7.1), the MDS Project up until recently has focused on the identification and collection of input datasets in collaboration with country teams in four African countries. This process has identified major gaps and deficiencies in existing data sources, considerable barriers to accessing such data, problems with validity and comparability of the data, and resource problems in assembling the input datasets. The process of accessing and capacity to analyze currently available data needs to be improved so that these data can be used more extensively. Routinely collected data provide the most sustainable source of high quality data and would provide opportunities for comparisons over a longer period.

As a result, current and future efforts to collaborate with countries in the African region should focus on the development of primary data collection, for example, through the World Health Survey (involving an oversample of older people and a longitudinal component) and on the strengthening of primary data collections to measure adult mortality (vital registration systems, sample registration systems and survey methods). Rigorous review of national WHS results will be needed along with comparisons to routinely collected data. Even with improvements in data collection systems, review of data will be needed. Results from recent analyses of causes of death in sub-populations in South Africa have shown that ill-defined causes were more common amongst older persons than other age groups. This would indicate that other methods, such as verbal autopsy methods, would add value to efforts to improve older adult mortality data. Verbal autopsy tools will play a key role in obtaining basic information on causes of death and there is a great need for validation studies to improve such instruments, and develop methods for probabilistic cause assignment instead of the currently widely used categorical algorithmic methods.

**Figure 7.1 MDS project priorities**



A second focus should be the continuing development of a minimum dataset of indicators, covering important quantities of policy interest. Such a dataset should contain a complete matrix of valid and comparable estimates for standard population categories (by age, sex, etc.), as well as metadata including reliability information and a data audit trail. Efforts to access and analyze available data must be continued, but with explicit directions and qualified colleagues/experts within the data holder systems (e.g. government statisticians). Training to extract data from existing sources, and harmonizing country data with primary data collection results will be necessary.

The development of such an indicator minimum dataset should be carried out in close collaboration with countries, with the WHO regional office, and with other international indicator development, particularly that associated with the Millennium Development Goals and with the proposed Health Metrics Network currently under discussion between WHO and other international bodies.

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## Annex 2. Minimum Data Set Project Indicators for MDS Version 1.0, submitted and known data by country

INDICATORS			GHANA				SOUTH AFRICA				TANZANIA				ZIMBABWE				WHS	
Indicator Number	Indicator Category	Indicator description (for current year, 2003)	Want data by sex?	Submit By Sex	Submit data	Data Source	Known Data	Submit By Sex	Submit data	Data Source	Known Data	Submit By Sex	Submit data	Data Source	Known Data	Submit By Sex	Submit data	Data Source	Known Data	Data will be available
1	Demographic Profile	Current population by 5-year age groups 50 to 80+ years, by urban/rural residence*	Y	Y	Y	Census 2000		Y	Y	Census 2001		N	Y	USCB	Census 2002	N	Y	ICDS 1997	Census 2002	Yes
2	Demographic Profile	Current total population, by urban/rural residence	Y	N	N		Census 2000	Y	Y	Census 1996	Census 2001	N	Y	USCB	Census 2002	N	N	ICDS 1997	Census 2002	Yes
3	Demographic Profile	Median age of population	Y	N	Y	Census 2000		Y	Y	Census 1996	Census 2001	N	N		Census 2002	N	Y	Census 1992	Census 2002	
4	Demographic Profile	2015 projected population by 5-year age groups 50 to 80+ years (with AIDS)	Y	N	N		Census 2000, USCB	Y	Y	USCB	Census 2001	N	N		Census 2002	N	N		Census 2002	
5	Demographic Profile	2015 projected total population (with AIDS)	Y	N	N		Census 2000, USCB	Y	Y	USCB	Census 2001	N	N		Census 2002	N	N		Census 2002	
6	Demographic Profile	2030 projected population by 5-year age groups 50 to 80+ years (with AIDS)	Y	N	N		Census 2000, USCB	Y	Y	USCB	Census 2001	N	N		Census 2002	N	N		Census 2002	
7	Demographic Profile	2030 projected total population (with AIDS)	Y	N	N		Census 2000, USCB	Y	Y	USCB	Census 2001	N	N		Census 2002	N	N		Census 2002	
8	Demographic Profile	Life expectancy, at birth (with AIDS)	Y	Y	Y	WHO	Census 2000	Y	Y	USCB, WHO		Y	Y	Census 1988, WHO	Census 2002, USCB	N	Y	ICDS 1997, WHO	Census 2002	
9	Demographic Profile	Life expectancy, at birth (without AIDS)	Y	N	N		Census 2000, 2002	Y	Y	USCB, MRC 2000		N	N		WHO, USCB	N	N		Census 2002	

10	Demographic Profile	Life expectancy, at 50, 60, 80 years	Y	N	N	WHO, USCB	Census 2000	Y	Y	MRC 2000	StatsSA	N	N		WHO, USCB	Y	Y	ICDS 1997	Census 2002	
11	Demographic Profile	Probability of death between ages 15 and 60 (45Q15)	Y	Y	Y	WHO	Census 2000	Y	Y	MRC, WHO	StatsSA	Y	Y	WHO	Census 2002	Y	Y	ICDS 1997	Census 2002	
12	Demographic Profile	Adult HIV prevalence	Y		Y	WHO	Nat'l AIDS Comm., UNAIDS	Y	Y	HSRC 2001		N	Y	WHO	NACP	N	Y	WHO		
13	Demographic Profile	Support/Dependency ratio (current year)	N	na	N		Census 2000	na	Y	Census 1996	Census 2001	na	Y	HBS/NBS 2000/01	Integrated LFS 2000/01	na	Y	ICDS 1997		
14	Demographic Profile	Support/Dependency Ratio of population aged 60+/15-59 years (current year)	N	na	N		Census 2000	na	Y	Census 1996	Census 2001	na	Y	HBS/NBS 2000/01	Integrated LFS 2000/01	na	Y	ICDS 1997		
15	Demographic Profile	Number of persons requiring daily care, by 10-year age groups 50 to 80+ years.	N	na	N		WHO	na	Y	WHO		na	Y	WHO		na	Y	WHO		
16	Social & Economic Status	Literacy rates 5-year age groups 50 to 80+ years by urban/rural residence (%)	Y	N	N		GLSS IV, CWIQ	Y	Y	OHS 1998	Census 1996, DHS 1998	N	Y	HBS 2000/01	Integrated LFS 2000/01	N	Y	ICDS 1997	Census 2002	
17	Social & Economic Status	Per cent highest level of education attained by 5-year age groups, 50 to 80+ years	Y	N	N		Census 2000, GLSS IV, CWIQ	Y	Y	Census 1996	Census 2001, DHS 1998	N	Y	HBS 2000/01		N	Y	ICDS 1997	Census 2002	Yes
18	Social & Economic Status	Per cent population by marital status (including polygynous unions), by 5-year age groups 50 to 80+ years	Y	N	N		Census 2000	Y	Y	Census 1996	Census 2001	N	Y	HBS 2000/01	Integrated LFS 2000/01	Y	Y	ICDS 1997	Census 2002	Yes
19	Social & Economic Status	Per cent HHs with ONE or more members aged 50+ years	N	na	Y		GLSS IV, CWIQ, Census 2000	na	Y	Census 1996	Census 2001	na	Y	HBS 2000/01		Na	N		Census 2002	Yes

20	Social & Economic Status	Per cent HHs headed by someone aged 50+ years	Y	N	N		Census 2000	Y	Y	Census 1996		N	Y	HBS 2000/01		Y	Y	ICDS 1997	Census 2002	
21	Social & Economic Status	Per cent of population aged 50+ years living alone	Y	N	N		Census 2000	Y	Y	Census 1996		N	Y	HBS 2000/01	Census 2002	N	N		Census 2002	Yes
22	Social & Economic Status	Per cent of HHs with head aged 50+ years and no other resident aged 15-49 years	Y	N	N		Census 2000	Y	Y	Census 1996		N	Y	HBS 2000/01		N	N		Census 2002	Yes
23	Social & Economic Status	Per cent economically active by 5-year age groups 50 to 80+ years	Y	N	N		Census 2000	Y	Y	Census 1996	DHS 1998	N	Y	HBS 2000/01	Integrated LFS 2000/01	Y	Y	ICDS 1997	1995 Poverty Assessment Study Survey	
24	Social & Economic Status	Per cent primary source of income by 5-year age groups 50 to 80+ years	Y	N	N		Census 2000	Y	Y	IES 2000	LFS 1995	N	Y	HBS/NBS 2000/01	Integrated LFS 2000/01	N	N		1995 Poverty Assessment Study Survey	
25	Social & Economic Status	Per cent with an assets indicator by 10-year age groups 50 to 80+ years	Y	N	N		GLSS IV, CWIQ	Y	Y	EPOP 2001		N	N		Integrated LFS 2000/01	N	N			Yes
26	Social & Economic Status	Per cent receiving social protection by source, 10-year age groups 50 to 80+ years	Y	N	Y	ILO		Y	Y	IES 2000		N	N			N	N			
27	Social & Economic Status	Headcount poverty ratios for 10-year age groups 50 to 80+ years (national poverty line)**	Y	N	N	WB	GLSS IV, CWIQ	Y	Y	IES 2000		N	Y	WB	HBS 2000/01	N	Y	WB	1995 Poverty Assessment Study Survey	
28	Social & Economic Status	Headcount poverty ratios for 10-year age groups 50 to 80+ years (international poverty line)	Y	N	N	WB	GLSS IV, CWIQ	Y	Y	IES 2000		N	Y	WB	Integrated LFS 2000/01 & PRSP 2000/01	N	N	WB	1995 Poverty Assessment Study Survey	

29	Social & Economic Status	Per cent of population aged 50+ years by type of main water source	N	na	N		Census 2000, GLSS or DHS 98	na	Y	Census 1996	DHS 1998	na	Y	HBS 2000/01		na	N		Census 2002, TDHS 1999	Yes
30	Social & Economic Status	Per cent of population aged 50+ years by type of main toilet facility	N	na	N		Census 2000, GLSS or DHS	na	Y	Census 1996	DHS 1998	na	Y	HBS 2000/01		na	N		Census 2002, TDHS 1999	Yes
31	Social & Economic Status	Per cent of population aged 50+ years by type of housing material	Y	N	N	Census 2000	GLSS IV or DHS 98	Y	Y	OHS 1999	DHS 1998	N	N		HBS 2000/01	N	N		Census 2002, TDHS 1999	
32	Health Status & Risk Factors	Cause specific mortality (proportional mortality) 10-year age groups 50 to 80+ years	Y	N	N		Births and Deaths, DHS 98?, Eastern Region Hospital Data	Y	Y	MRC 2000	BoD 2000	N	N		BoD 2001, MoH, AMMP	N	N		BoD 1997	Yes
33	Health Status & Risk Factors	Per cent of population aged 50+ years by self-rated health status	Y	N	N		WHS	Y	Y	OHS 1999	WHS	N	N		BoD 2001, MoH, AMMP	N	N		WHS	Yes
34	Health Status & Risk Factors	Per cent reported tobacco use, by age 50+ years	Y	N	N		WHS	Y	Y	OHS 1996		N	N		WHS	N	N		WHS	Yes
35	Health Status & Risk Factors	Per cent reported daily alcohol consumption, by age 50+ years	Y	N	N		WHS	Y	Y	DHS 1998		N	N		WHS	N	N		WHS	Yes
36	Health Status & Risk Factors	Per cent reported physical activity/inactivity, by age 50+ years	Y	N	N		WHS	N	N	HSRC 1991		N	N		WHS	N	N		WHS	Yes
37	Health Status & Risk Factors	Per cent reported intake of fruit and vegetable, by age 50+ years	Y	N	N		WHS	N	N		UCT 2002	N	N		WHS	N	N		WHS	Yes

38	Health Care Services	Per cent visiting health facility in last 30 days, by age 50+	Y	N	N		DHS 98, WHS	Y	Y	OHS 1998		N	Y	HBS/NBS 2000/01	WHS	N	N		WHS	Yes
39	Health Care Services	Per cent visiting traditional healer in last 30 days, by age 50+	Y	N	N		DHS 98?, DSS	Y	Y	OHS 1998		N	N		?	N	N		?	
40	Social Integration / Well-being	Per cent of population with children living within one hour travel time to person aged 50+ years	Y	N	N		?	Y	Y	HSRC 1991		N	N		?	N	N		?	
41	Social Integration / Well-being	Per cent of population with no remaining family, by age 50+ years	Y	N	N		?	Y	Y	Census 1996		N	N		?	N	N		?	
42	Social Integration / Well-being	Per cent of population reporting loneliness, by age 50+ years	Y	N	N		WHS	Y	Y	HSCR 1991	WHS	N	N		whs	N	N		WHS	Yes
43	Social Integration / Well-being	Per cent of population who voted in last election, by age 50+ years	Y	N	N		WHS	Y	Y	EPOP 1999	OHS 2000, WHS	N	N		WHS	N	N		WHS	Yes
*Definition of urban and rural for each country needed: rural definitions include population totals per area (e.g. Ghana < 5,000; Zimbabwe < 20,000) or area type and service provision (e.g. South Africa = non-metropolitan area; and Tanzania = those areas not designated as cities, municipalities, town and township councils as well as designated planning (trading centre) areas).																				
** National monetary poverty line: (UNITS: %, in local currency and US\$, PPP). National definitions to be provided by each country.																				
<b>EXPANDED SET</b>																				
44	Health Status & Risk Factors	Percent of children under 15 years in a household survey whose mother and father died	Y	N	N		UNAIDS/DHS	N	N		UNAIDS/DHS, AIDS Study	N	N		UNAIDS/DHS	N	N		UNAIDS/DHS	
45	Health Status & Risk Factors	Percent of households for whom a grandparent /person aged 50+ years is reported as the primary caretaker for orphaned children.	Y	N	N		WB 2003, DHS	N	N		WB 2003, DHS				WB 2003, DHS				WB 2003, DHS	

<b>46</b>		Percent of older population, by 10-year age groups, migrating in last 5 years, by internal or external migration.																
<b>47</b>		Percent of older persons, by 5-year age groups, who reported having selected chronic conditions, by number (none, one, two, or three or more).																
<b>48</b>		Percentage of older persons, by 5-year age groups, who are unable to perform certain physical functions (e.g. ADL).																
<b>49</b>		Percentage of older persons, by 5-year age groups, who are unable to perform certain physical/social functions (e.g. IADL).																
<b>50</b>	Social Integration / Well-being	Life satisfaction index. "How satisfied are you with your life these days?"	Y	N	N			Y	Y	HSCR 1991	Rhodes Univ	N	N			N	N	
<b>51</b>	Social Integration / Well-being	Global happiness index: "Taking all things together, how happy would you say you are these days?"	Y	N	N			Y	Y	HSCR 1991	Rhodes Univ	N	N			N	N	

### **Annex 3. Towards an MDS Dissemination and Use Strategy – Draft**

To date, the focus of the MDS has been on the indicators and input data needed to provide comprehensive information to inform policy and programme development on ageing. At this workshop, one of the actions agreed was to develop a strategy for the dissemination of information being generated by the MDS Project. Subsequently, a consultative process took place involving the four MDS country teams and other colleagues who had participated in the workshop. This strategy has been generated from the many valuable ideas and suggestions made during and immediately after the workshop. It is for use by country teams and others as they plan dissemination of the findings and process of the MDS.

It is understood that the methods and processes created need to be further refined to contribute fully to development efforts. The results produced can be used as the first step in this process. Beyond use of the data, for example, a revised set of indicators should be used at many levels: to inform country application of the AU Framework; to improve poverty reduction efforts in vulnerable older persons as part of the PRSPs; and to be incorporated into national development efforts towards meeting the Millennium Development Goals. The indicators can also be used by the Health Metrics Network, to produce data of assured quality. Linking the MDS into these processes will decrease the burden of data collection and management, while increasing the impact and intended result of improving the health status and development of older persons.

#### **Target Audiences**

Information generated by the MDS has many uses and will be of interest to a wide variety of stakeholders. However, for the MDS to achieve its objective of helping promote and enable informed policy development there is also need for information to be targeted at specific audiences. Key target audiences at national, regional and international include:

- African governments at national and provincial levels, with information targeted at specific Ministries, Departments, Directorates and individuals;
- Universities, research institutions and individual researchers. In particular, those focused on ageing and population issues and those involved in policy development processes. Global research organizations to encourage funding of research to fill information gaps;
- Bodies developing and implement poverty reduction policies and programmes, including those responsible for the production of PRSPs;
- Regional bodies such as the AU and NEPAD;
- Older people themselves and age-focused organizations at provincial, national, regional and international levels;
- African and international NGOs and intergovernmental organizations such as the UN; and,
- Funding agencies.

#### **Informing Debates**

The dissemination of MDS data will help inform policy, programme and research agendas on ageing and related fields. To achieve this, information needs to be carefully packaged and targeted to meet the needs and interests of different audiences. To ensure that the MDS is seen as relevant, there is need to link it to other on-going processes e.g. development of country development plans, PRSPs, NEPAD, MDGs. The information from the MDS will provide data to inform debates in the following specific areas:

- Define the impact of HIV/AIDS on older people to influence resource allocations from the global fund as well as local budget allocations;
- Strengthen and support existing health information and health care systems to ensure that issues of ageing are represented and understood;
- Determine health status, behaviours and risk factors.
- Attention to the rights, health status, social security and abuse of older persons within the same debates about younger adults and children.
- Create action based research – MDS to link research and policy, helping inform and strengthen existing research and highlighting gaps based on documented needs.

### **Presenting Information to Different Audiences**

Whilst the information generated by the MDS has many possible applications, there is need to package the information in different ways for different audiences to encourage its use and application. Issues to be considered in doing this include:

- Different audiences need to be targeted with packages of information that reflect their information needs and interests. As well as presenting data, there is need to help with analysis and interpretation;
- For each audience, appropriate channels of communication (including both print and electronic) need to be utilized as different people have access to and utilize different media;
- Effective consultation with age-focused NGOs and government departments will help support the dissemination and use of information;
- Country MDS reports should be written and used as the basis for creating materials for dissemination;
- Dissemination meetings to present results and data, what it means and how it can be utilized to inform national and regional policy development. Thematic seminars could help target specific groups of policy makers and other key stakeholder;
- During dissemination events, presentations by older people about their needs and concerns may help create understanding of why the data is needed and the reality behind the numbers; and,
- Fact sheets on different issues should prepared in hard copy and made available on the web.

### **Communication Channels**

A wide variety of channels exist for the dissemination of information from the MDS Project, these include:

- Local organizations closely involved in the creation of the MDS could utilize their existing communication channels including media, journals and webpages;
- Links between the MDS Project website and other webpages;
- National Bureaus of Statistics documents;
- Where internet access is poor, presentation of data on CDs and hardcopy;
- Journal publications – including those that focus on health, ageing and development, as well as other sectoral issues such as population, sociology, HIV/AIDS and demographics;
- International fora on population and/or ageing e.g. workshops and meetings;
- Inclusion in UNFPA – State of the World Population Report; and,
- E-newsletters as a means of disseminating information about the web-sites and available data.

### **Monitoring and Evaluation**

Monitoring and evaluation processes need to be established to assess the extent to which the dissemination plans meet their objectives.

- Indicators (for both national and international monitoring) should be identified to be able to assess whether information reaches different audiences, how they use the information and then if it adds value to policy and planning. Indicators could include the number of web-site hits, requests for data and others;
- The uptake of indicators by governmental and international agencies monitoring Millennium Development Goals and as part of the Health Metrics Network; and,
- At country level, small surveys could be undertaken to assess utilization of data and determine which means of communication have been used to access the information.

### **Other Issues**

- Recognition of the project by WHO country offices is essential.
- At country level, the participation of relevant government staff in on-going MDS/WHS processes will help dissemination, promote ownership and link the MDS to other policy and information processes.
- Use experience in developing indicators to influence inclusion in other processes, such as the Health Metrics Network and Millennium Development Goals.