WHO Reference Group on Global Health Statistics (RGHS)

14-15 March 2017

Geneva, Switzerland

Report & Recommendations

The WHO Reference Group on Global Health Statistics (RGHS) provides advice on population-health related statistics of relevance to WHO, with particular focus on mortality and causes of death. The third RGHS meeting took place on 14-15 March 2017, attended by experts, UN agencies, and funding agencies.

Background

In 2013, WHO established a Reference Group on Global Health Statistics (RGHS), supported by the Bill & Melinda Gates Foundation. The RGHS provides advice on the broad range of population-health related statistics of relevance to WHO, including adult mortality and life tables, causes of death, and standards for calculating and reporting health statistics. The RGHS also provides a platform for debate and collaboration with other institutions that produce health estimates, including IHME, MCEE, IGME, and the UN Population Division. WHO convened an initial meeting of the RGHS in December 2013, at which the RGHS and secretariat agreed on a two-year work program for the Reference Group. The work program included four work streams: 1) verbal autopsy, 2) life tables, 3) development of Guidelines for Accurate and Transparent Health Estimates Reporting (GATHER), and 4) use of health statistics in countries. The two-year work program concluded at a meeting of the full RGHS in March, 2016, at which the four working groups reported back on their progress.

With the establishment of the Sustainable Development Goals (SDGs), WHO must now embark upon monitoring a new suite of health indicators. The SDGs include one health goal with 13 targets and 26 indicators, and at least two dozen health-related indicators in the other 16 goals (Table 1). Thirteen of the indicators require information on total- or cause-specific mortality. The RGHS meeting in March, 2016 emphasized the leadership role of WHO in monitoring the health-related SDGs. The RGHS recommended that WHO develop metadata for the SDG health indicators and provide guidance to countries on “best practices” for data collection and analysis on each SDG health indicator. This includes advice on strengthening health information systems, in collaboration with partners through the Health Data Collaborative; on data quality assessment, including analytical methods to overcome specific limitations; and tools that countries may use to calculate SDG indicators. The World Health Assembly has also requested annual reporting of progress toward the health-related targets, which involves carrying out a similar set of activities. Given the prominence of mortality, and especially mortality by cause, in the SDG targets and indicators, the RGHS meeting in March, 2017 focused on monitoring the mortality-related SDGs. The meeting specifically covered the challenges of monitoring mortality by cause in different settings, including those with high-quality death registration systems and those with developing systems. A summary of the meeting and the RGHS recommendations to WHO follows.

Table 1. Selected health-related SDG indicators.

3.1.1	***Maternal mortality***	**3.a.1**	**Tobacco use**
3.1.2	Skilled birth attendance	**3.b.1**	**Immunization coverage**
3.2.1	*Under-five mortality rate*	3.b.2	R&D development assistance
3.2.2	*Neonatal mortality rate*	**3.b.3**	**Essential medicines**
3.3.1	HIV incidence	**3.c.1**	**Health workers**
3.3.2	**TB incidence**	**3.d.1**	**IHR capacity and emergency preparedness**
3.3.3	**Malaria incidence**	1.a.2	Proportion of government spending on services
3.3.4	**Hepatitis B incidence**	2.2.1	Stunting among children
3.3.5	**Neglected tropical diseases at risk**	2.2.2	Wasting and overweight among children
3.4.1	***Mortality due to NCD***	**5.2.1**	**Intimate partner violence among women**
3.4.2	***Suicide mortality rate***	5.3.2	Female genital mutilation
3.5.1	**Treatment substance use disorders**	**6.1.1**	**Drinking water services**
3.5.2	**Alcohol use**	**6.2.1**	**Safely managed sanitation services**
3.6.1	***Deaths from road traffic injuries***	**7.1.2**	**Clean household energy**
3.7.1	Family planning	8.8.1	*Occupational injury mortality*
3.7.2	Adolescent birth rate	**11.6.2**	**Air pollution**
3.8.1	**Coverage of essential health services**	13.1.2	*Mortality due to disasters*
3.8.2	**Financial protection**	**16.1.1**	***Homicide***
3.9.1	***Mortality due to air pollution***	16.1.2	*Mortality due to conflicts*
3.9.2	***Mortality due to WASH***	16.1.3	Population subject to violence
3.9.3	***Mortality due unintentional poisoning***	17.19.2	Birth and death registration coverage

Note: Indicators for which WHO is custodian are bolded. Indicators requiring data on mortality are in italics.

Overview of current and planned WHO work in the context of the SDGs

In this session, WHO staff presented current work in the areas of SDG monitoring, total mortality and causes of death, and reporting of health estimates (GATHER). The following themes emerged:

- The SDGs imply a larger scope of monitoring as compared to the MDGS, with a major expansion in goals, targets and indicators. The more than 40 health-related SDG indicators in Table 1 can be grouped into 7 categories: reproductive, maternal, nutritional and child health; priority infectious diseases; noncommunicable diseases and injuries; environment; violence; and means of implementation; and universal health coverage.
- There are two major revisions to the monitoring process as compared to the MDGs: first, a notion that the monitoring will be country-led rather than led by the UN agencies, and second, a focus on equity, which requires greater disaggregation of data.
- Innovation is needed in order to present the evidence basis of health estimates; although GATHER requires quantification of uncertainty, current methods result in underestimates of uncertainty and are generally ignored by users. The UNSD has proposed data labels: Country, Country-adjusted, Estimated, Modeled; these labels are meant to provide information on the evidence basis underlying a set of estimates. WHO has proposed reviewing and extending these labels to the Global Health Observatory, potentially using a quantitative measure of the extent to which an estimate is informed by data from the same population.

- WHO has several ongoing activities to monitor the health-related SDGs, which include the annual publication of the World Health Statistics, the 100 Core Health Indicators, and the Global Health Observatory.
- Key issues for WHO include continued activities in the area of producing life tables and comprehensive causes of death data, challenges in disaggregation of health monitoring data, need for innovation around the country consultation model, communication of data underlying estimates, and uptake of global burden of disease methods and/or results.

Recommendations for WHO

- WHO must continue to support data collection in countries, with an emphasis on increasing the quality of data collected by countries. This includes advising on best practices for monitoring the health-related SDGs, building upon the Global Reference List of 100 Core Health Indicators. WHO should especially support countries in making primary data available for monitoring and research processes.
- Household surveys must be the backbone of equity monitoring. WHO should collate survey modules to support country monitoring of SDGs; ideally WHO would have a model World Health Examination survey series. This should be a priority for WHO investment.
- One must deal with improving/changing data quality carefully in modelling exercises, to avoid misinterpretation of changes in quality as trends (e.g., the transition from ICD-10 to ICD-11).
- The group endorsed proposed activities in the area of GATHER curation, including improvements in the meta-data for the data in the Mortality Database and identification of the evidence basis of data in the Global Health Observatory.
    - The analysis framework proposed in GATHER, including consideration of major sources of bias in measurement data, and the principles of transparency espoused by GATHER are beneficial for countries. WHO should promote GATHER concepts in countries.

Updates from health estimates research groups

This session provided an opportunity for UN reference groups and the IHME to review new developments in health estimation, as well as future research plans.

- IHME will release GBD annually in September, with incremental updates each year. An overview of recent advances and main research priorities was given. Other expected outputs for 2017/2018 include: personal health care access and quality estimates (May 2017), India subnational estimates (Nov 2017), health workforce estimates (GBD2017), health system performance assessment (2018).
- The Health Data Collaborative aims to rationalize data collection in countries, to reduce the amount of time health workers and professionals spend collating and reporting data.
- UN IGME's main areas of research are estimation of child mortality by wealth quintile, extension of estimates to the age range 5-14, and to improve estimates of child mortality by finer age groups.
- UNAIDS presented their collaborative model for estimates generation, which involves training over 600 national counterparts and partners on the Spectrum models. This work is resource-intensive. They are facing increasing demands for real-time, subnational, and age-

specific estimates, and are rolling out several advances in response to these demands. A major focus of work is to ensure the models are relevant for policy and planning analysis.

- MMEIG has set a high bar in documenting data and methods since 2010, when all data inputs and statistical code were published on the WHO website. Current areas of research are to update the adjustment for misclassification in death registration, and assessments of VR and survey data quality, as well as improvements of covariates, and advice to countries on data collection and validation.

Recommendations for WHO

- The reference group expressed support for work with countries, in particular by holding regional workshops on methods. The UNAIDS model of socially robust estimates is the way forward for use of knowledge gained from estimation processes in countries for decision-making.

Challenges in total mortality estimates

This session focused on two areas of concern for WHO, which are the discrepancy between mortality estimates in the age range 5-14 between the UN and IHME, and coherence of UNAIDs and total mortality estimates from the UN Population Division.

- Work on mortality for children and adolescents aged 5-14 using full birth histories was presented as a viable way forward, allowing for empirical estimation of mortality in this age range in place of reliance on model life tables. Estimates based on IGME methods and data from 140 countries have shown that total mortality in this age range is likely between UN and IHME levels, and that mortality rates are declining, but not as quickly as child mortality. IHME expressed interest in moving toward this type of approach.
- Jeff Eaton presented initial results from an expanded version of the UNAIDS Spectrum model that implements a more comprehensive demographic structure in the underlying transmission model, along with simultaneous fitting to HIV prevalence and mortality data. Once fully developed, this approach could reconcile the large differences in estimated mortality for countries with high HIV burden obtained from demographic methods (e.g., from UNPD) vs. a dynamic model (e.g., from UNAIDS).

Recommendations for WHO

- WHO should support University of Louvain-IGME work on mortality in the age range 5-14, and consider adopting it in future life tables work.
- The assumption of independence in record linkage (capture-recapture) studies is a strong assumption. These studies should be used to assess completeness of death registration only if three or more systems are linked.

Malaria estimation

WHO and IHME estimates of malaria deaths differ substantially.

- Challenges in assignment of underlying cause of death, in the presence of multiple contributing infections, was discussed. Methodological challenges are the reason for differences in estimates by research group.

- It was stated that estimates of malaria mortality from multiple sources are converging, due to improvements in conversations. However current estimates from IHME and WHO are still far apart - adult mortality is 2 times higher in GBD2015 as compared to WHO's malaria mortality estimates for 2015, and child mortality is 1.5 times higher.

Recommendations for WHO

- Positive collaborative work has occurred to date in bringing WHO and IHME estimates closer together. Further work should be done in this area to resolve differences.

Causes of death in death registration data

This session focused on analysis of death registration data for the sustainable development goal cause-specific mortality indicators.

- The concept of garbage codes-- ICD codes which are not useful for understanding causes of death from a public health perspective--was discussed. The use of the term garbage code was discussed, and although group members did not support the term, there was no consensus around alternate terms. The terms "ill-defined," "recycle" and "invalid" codes were proposed.
- WHO presented current methods in garbage code redistribution. In order to ensure smooth collaboration and consistent advice to countries, WHO wishes to follow a set of redistribution algorithms that is simple and stable over time.
- IHME presented their latest work in the area of garbage codes. IHME uses a complex and comprehensive set of redistribution algorithms with multiple methodologies used. To improve communication about garbage codes, these have been subdivided into major and minor codes, with major codes being redistributed across broad cause groups (e.g., death, cause unknown) and minor codes being redistributed within cause groups (e.g., stroke, type unknown). IHME has introduced a star rating for the quality of mortality underlying mortality estimates by cause. For CRVS, this rating is based on the concept of fraction of deaths that are well-certified – a concept similar to the usability concept WHO has been using for several years.
- Validation of garbage code redistribution algorithms was discussed. Autopsy studies may be used, but pathologists may determine the mode of death rather than the underlying cause of death. There is also a selection bias on autopsies, as they are more likely to be performed on the most challenging cases – autopsy rate must be high for the data to be useful. Hospital/medical record linkage studies are more promising, but the challenge is that at the oldest ages, individuals may have many hospital admissions for diverse causes.
- Assignment of suicide as an underlying cause of death was discussed. Suicide deaths in particular may vary because of how injury deaths are certified, e.g., coronial vs. medico-legal systems use different thresholds of certainty to assign suicide. Coronial systems are less likely to assign probable suicide to undetermined intent. In some countries, suicide is still criminalized and there are implications for life insurance or pensions, leading to family requests not to place suicide on the death certificate. Surveillance systems such as Ireland's Regional Suicide Surveillance System can be used to highlight weaknesses of CRVS data.
- An update on the 11th revision of the International Classification of Diseases (ICD-11) was given. The implementation version is planned for release in 2018.

- PAHO efforts to expand collection and collation of mortality data were presented. A major effort was undertaken to analyze death certificates in use in member states, and expand the variables included in PAHO's mortality database from 5 to 34. Effort is also being made to seek missing years of data. Currently, multiple causes of death data from 10 countries have been collated by PAHO. WHO proposes following PAHO's example at the global level, with additional work in the areas of ethics, security and data sharing policy; WHO will also work to integrate SMoL data being collected in DHIS2 systems.

Recommendations for WHO

- The RGHS recommended that WHO proceed with country work on garbage code redistribution methods. Country awareness of issues is key, because it has the potential to lead to better ICD coding at the country level. A system of rating country death registration data, such as IHME's star rating system or color codes that WHO is using to illustrate quality of death registration system, should be adopted and publicized by WHO to encourage countries to improve quality and submit data.
- The RGHS strongly recommended favouring continuity over change in the ICD-11 revision. The group also recommended paying particular attention to designing ICD-11 hierarchies to minimize the potential use of garbage codes. External cause categories and axes should be reviewed to focus on causes of public health importance and reduce the number of categories. Overlap conditions – conditions with more than one valid underlying cause of death in the causal chain – are a large challenge because assignment to the underlying cause of death is quite random. An example of this is CKD due to diabetes. Generally, these should be grouped together at the more basic level (CKD).
- The importance of ICD rules for assignment of cause-of-death was emphasized. Rule changes introduced in the course of ICD-10 had major effects on specific causes of death such as falls and unintentional poisonings, with timings and effects that varied by country. In addition, rules can clarify when diseases like diabetes and essential hypertension can be considered underlying causes of death. Currently diabetes mortality and prevalence are uncorrelated. These seriously impede monitoring mortality from SDG and other causes of death. Stable and sensible rules will be key to ensure ICD-11 supports public health monitoring.
- WHO should seek advice and inputs on the ICD-11 revision process from groups with experience in the use of multi-country and subnational analysis of ICD-coded causes of death. RGHS members, including Chris Murray, have volunteered to be involved in this process.
- The RGHS gave the following specific recommendations on ICD-11 revision:
    - RGHS did not object to the placement of cerebrovascular conditions in the chapter 'Diseases of the Nervous system', but emphasized that for analysis it would still be grouped with cardiovascular diseases.
    - Alzheimer's disease, vascular dementia, and unspecified dementia should be grouped together in the chapter 'Diseases of the Nervous system'. Other dementias which are sequelae of specific diseases, such as Parkinson's, should remain together with the underlying disease.
    - Road/non-road should be the first axis of categorization for the transport injury classification and reduce creation of potential garbage codes.
- The RGHS supported the proposed expansion of the WHO mortality database, following the example of PAHO and including the additional meta-data around populations covered.

RGHS members, including David Blazes and Sam Clark, will advise on the project. Inclusion of SMoL data was of particular interest, as it now has national implementation in 13 countries via DHIS2.

Monitoring during CRVS systems strengthening

This session had two goals: first, to lay out tools for CRVS strengthening, and second, to take stock of opportunities and challenges in monitoring cause-specific mortality during CRVS strengthening, i.e., when death registration data are still too poor to be used reliably for monitoring.

- The experience of 5 Asian countries with sample registration systems was presented. The systems have quite variable institutional basis and reception by country researchers. Although of proven value as a reliable source of national vital statistics, generally, these are not well integrated with civil registration systems, and this impedes overall health information systems strengthening in terms of moving towards reliable data sources for monitoring SDGs at subnational level.
- Experience with MITS (minimally invasive tissue sampling) was also presented, in the context of two major Gates-funded projects: CHAMPS and COMSA. CHAMPS is a population-based MITS study, while COMSA is an SRS system with VA and limited MITS to evaluate the quality of VA. The study researchers are continuing to find high acceptability of MITS, based on next-of-kins' desire to understand the death of the child. MITs has potential for further clarifying the accuracy of VA.
- An overview of methods for the assessment of completeness of death registration was given. In general, recommendation is to use multiple independent data sources and multiple methods as much as possible, as single methods are subject to bias and error.
- Suitability of VA for monitoring mortality by cause for non-communicable diseases and injuries was discussed. For NCDs, sensitivity for specific causes tends to be low (37-71%). Sensitivity is best for some particular cancer sites. Specificity tends to be quite a bit higher than sensitivity (~98%). VA performs better for injuries, and in particular road traffic looks to be the most accurately measured and stable. IHME currently only uses physician-certified VA, with an exception for some injuries.

Recommendations for WHO:

- Full death registration with medical certification of cause of death should be the goal of all systems strengthening. However, these take decades to fully implement, and it is necessary to monitor mortality in the medium term for policy purposes. Sample registration systems can be set up more quickly. The key is to ensure integration with CRVS systems for mutual strengthening.
- Verbal autopsy results should be treated cautiously for monitoring trends in NCDs and even injuries. For data to be usable for monitoring, it is important to use a consistent sampling method, verbal autopsy instrument, and analysis method. Changes in methodology can easily obscure trends in cause fractions. Even if methodology is constant, fixed sensitivity and specificity can bias the trend of a particular cause.

Conclusions

The RGHS recommended continuation of the RGHS platform. Future meetings would be improved by a careful framing of discussions by WHO, with introductory materials shared ahead of the meeting. WHO should continue to provide advice to countries on monitoring SDG indicators, including advice on analysis of death registration data. WHO will also continue to make estimates for priority conditions, leveraging its need to consult with member states on methods and results. A strategic priority of WHO should be enhanced assessment and communication of the quality of data collected in countries, and data underlying WHO estimates. This is an area where WHO can leverage its norms and standards function and its monitoring function to identify weaknesses and gaps, and encourage countries to improve their health information systems.

Annex A: Agenda

Tuesday, March 14

Time	Title	Presenters
	Current and planned WHO work in the context of the SDG	
08:30	Welcome coffee	
09:00	Introductions, background and objectives	Ties Boerma
09:15	WHO engagement with the health-related SDGs	Dan Hogan
09:45	WHO methods for estimating total- and cause-specific mortality	Colin Mathers
10:15	GATHER: update and future plans	Gretchen Stevens
10:30	Use of estimates in countries: update	Ties Boerma
10:45	*Coffee break*	
	Updates from health estimates research groups	
Objective	*Review new developments in health estimation: IHME & UN health estimates (Chair: Ties Boerma)*	
11:20	GBD2016	Chris Murray
11:40	Health Data Collaborative IGME UNAIDS MMEIG	Alistair Robb Bob Black / Danzhen You Jeff Eaton / Mary Mahy Mohamed Ali
12:40	*Lunch*	
	Challenges in total mortality estimation	
Objective	*Advice on path forward for total mortality estimation (Chair: Colin Mathers)*	
14:00	IHME life tables update	Chris Murray
14:20	Adolescent mortality	Bruno Masquelier
14:40	HIV and adult mortality in sub-Saharan Africa	Jeff Eaton
15:00	Discussion	
15:30	*Coffee break*	
	Malaria mortality: toward consistent estimates	
Objective	*Advice on research priorities in the area of malaria estimation (Chair: Simon Hay)*	
16:00	Overview of challenges: adult and p vivax mortality and population at risk	Richard Cibulskis
16:20	GBD malaria mortality estimates	Pete Gething
16:40	Severe malaria	Tom Smith
17:00	Discussion	
18:00	Close of day 1	
18:30	Reception at WHO cafeteria	

Wednesday, March 15

Time	Title	Presenters
	Causes of death in CRVS (focus on SDG 3.4)	
Objective	*Advice on analysis of CRVS data for SDG causes (Chair: Rafael Lozano)*	
08:30	Welcome coffee	
09:00	Challenges in cause of death assignment in CRVS: WHO perspective	Gretchen Stevens
09:15	IHME methods for miscoding and leading garbage codes	Chris Murray
10:00	Challenges in measurement of suicide deaths in CRVS data	Ella Arensman
10:20	*Coffee break*	
10:50	ICD 11th revision general update: update and report of July meeting	Robert Jakob Colin Mathers
11:20	PAHO mortality data collection: update	Gerardo de Cosio
11:35	WHO mortality database: update and plans	Doris Ma Fat
11:50	Discussion	
12:10	*Lunch*	
	Monitoring during CRVS system strengthening	
Objective	*Overview of tools for monitoring mortality levels & causes during CRVS system strengthening (Chair: Shams el-Arifeen)*	
13:10	Overview on improving vital statistics during CRVS strengthening	Anneke Schmider
13:30	SRS systems: overview and applications in Asia	Chalapati Rao
13:50	Potential & limitations of autopsy through MITS	Tamer Farag
14:10	Update on using SMoL to record hospital deaths	Doris Ma Fat
14:30	*Coffee break*	
Objective	*Advice on monitoring mortality levels & causes during CRVS system strengthening (Chair: Sam Clark)*	
15:00	Lessons learned on evaluating completeness of registered deaths	Patrick Gerland
15:20	VA strengths and weaknesses for monitoring and for new priority adult causes (SDGs)	Daniel Chandramohan
15:40	IHME methods for use of VA data to estimate mortality by cause	Chris Murray
16:20	Discussion	
17:00	Summary of meeting	Ties Boerma
17:15	End of meeting	

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