



**DRAFT REPORT**  
**Cross-Regional Mortality Statistics**  
**Expert Workshop**  
**Cairo, Egypt, 28 September – 1 October 2015**

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## **Ministerial Statement: 3rd Conference of African Ministers Responsible for Civil Registration**

Republic of Cote d'Ivoire Feb 2015

*'...Recognizing that the Ebola epidemic has shown that the need for death registration and real time cause-of-death information is no longer optional but critical;*

*....Realising the centrality of civil registration based vital statistics in providing data to inform health, economic and social policies, for good governance and accountability, and in advancing the data revolution;*

*....Appreciating the increased and continuing involvement of the African Ministers of Health in improving registration of births and deaths, including the collection of information on cause-of-death;*

*....Underscoring the important role of the health sector in the delivery of civil registration services to ensure a coordinated and integrated approach in addressing the challenges of improving CRVS systems in Africa;*

***....Call upon WHO, in collaboration with Pan African Organizations and other partners, to intensify their efforts in developing real time death registration and causes of death information systems at country level'***

## **Resolution of the 8th African Symposium on Statistical Development**

Republic of Cote d'Ivoire Nov, 2012

*....Noting with concern low levels of death registration and certification of causes of death in African countries and acknowledging the importance and appropriateness of the theme for the 8th ASSD;*

***....Call upon WHO, HMN, In-Depth and other relevant partners to support the country plans on innovation and capacity building for improvement of death registration and causes of death.***

## Acronyms and Abbreviations

|                        |  |
|------------------------|--|
| <b>ACME</b>            | Automated Classification of Medical Entities   |
| <b>AIDS</b>            | Acquired Immune Deficiency Syndrome  |
| <b>APAI-CRVS</b>       | Africa Programme on Accelerated Improvement of Civil Registration and Vital Statistics   |
| <b>ASSD</b>            | Africa Symposium on Statistical Development  |
| <b>CHW</b>             | Community Health Worker  |
| <b>CDC</b>             | Centers for Disease Control and Prevention   |
| <b>CoD</b>             | Cause of Death   |
| <b>CRVS</b>            | Civil Registration and Vital Statistics  |
| <b>DHIS</b>            | District Health Information Software   |
| <b>EMRO</b>            | Eastern Mediterranean Regional Office  |
| <b>HDSS</b>            | Health and Demographic Surveillance System   |
| <b>HIV</b>             | Human Immune deficiency virus  |
| <b>HMN</b>             | Health Metrics Network   |
| <b>ICD</b>             | International Classification of Diseases   |
| <b>IRIS</b>            | An automatic system for coding multiple causes of death and for the selection of the underlying cause of death                     |
| <b>INDEPTH NETWORK</b> | International Network of field sites with continuous Demographic Evaluation of Population and Their Health in developing countries |
| <b>MDGs</b>            | Millennium Development Goals   |
| <b>MOU</b>             | Memorandum of Understanding  |
| <b>NSDS</b>            | National Strategy for Statistical Development  |
| <b>SAVVY</b>           | Sample Registration with Verbal Autopsy  |
| <b>SDGs</b>            | Sustainable Development Goals  |
| <b>TWG</b>             | Technical Working Group  |
| <b>UNECA</b>           | United Nations Economic Commission for Africa  |
| <b>UNFPA</b>           | United Nations Population Fund   |
| <b>VA</b>              | Verbal Autopsy   |
| <b>WHO</b>             | World Health Organization  |

## Executive Summary

Mortality and cause of death (CoD) statistics are primary requirements for the management of national health programmes, including defining immediate interventions for disease outbreaks and epidemics. In Africa, mortality statistics systems in most countries are weak, often characterized by fragmented and uncoordinated collections from multiple sources. As a result, African countries lack continuous, permanent and universal sources of mortality data, and thereby face considerable challenges in developing health interventions and building health systems, measuring and monitoring mortality, and in reporting against national and global development mortality goals and targets, such as those set by the Millennium Development Goals.

The evidence of this weakness is visible in the lack of real-time mortality data available in the Ebola outbreak recently experienced in Western Africa. During their 3<sup>rd</sup> conference held in Cote d'Ivoire in February 2015, African Ministers responsible for Civil Registration took note of this situation and made an urgent call on the World Health Organization (WHO) and its pan-African partners to take urgent steps towards supporting African states to establish real time death registration and cause of death information systems.

A five-year strategy was developed to directly address this ministerial call. The overarching objective is to make readily available continuous, harmonized, quality mortality and cause of death data and statistics for African countries, guiding the development of better planned, designed and integrated mortality systems. A regional reference group was formed in August 2015 to consider how best to progress mortality statistics as an agenda within the APAI-CRVS programme in Africa.

The group identified that the challenges are many; including multiple fragmented and uncoordinated systems, the incorrect perception of a lack of regional expertise, and a lack of regional institutions to provide support. The regional reference group also agreed that a meeting of experts be held, at WHO EMRO's invitation in Cairo, Egypt. The purpose of the meeting was to gather African experts in mortality statistics collections together to **collaborate on new technical guidance** to be provided to countries for designing better mortality statistics systems; and to **develop a pool of available experts** to deploy to countries to support technical improvement and results in mortality data collections, especially for death registration, hospital deaths and integrating systems for community deaths.

This report focusses on:

- information, presentations and discussions at the Cairo Workshop; and
- synthesis of key meeting outcomes for WHO, UNECA and African partners action.

## Meeting outcomes

Synthesizing the expert discussions and presentations, the meeting highlighted the need for further attention in the following areas.

### Standards, Guidance, Methodology

There is an increasing need to develop and make accessible the required standards, methodologies, and guidelines that support African countries in improving mortality and cause of death collections. The resources recommended to be developed and provided to countries by WHO, UNECA and African partners are three-fold:

- **Online and printable resource** designed for country guidance and planning on health facilities collections and ICD; community deaths; data linkage for administrative and other data; samples surveys, census; and special or difficult collections (such as emergency settings).
- **Methodology development** based on case studies and country experiences. Many issues were raised that require a methodological focus on developing concepts and guidelines to improve mortality data collection and analysis in Africa. A small methodology group was formed at the workshop that would be responsible for the development of concepts and methodology guidance.
- **Technical development:** Further development of technical guidance and resources and building of in-depth expertise and capacity.

### Priority Development Areas

Using adaptive, scaled approaches to support changing needs in countries, it was recommended that there was a need for country guidance to focus on:

- **Focussing on country plans for better design for mortality statistics as a system**, focussed on improving death registration, hospital mortality data and community deaths data, and incorporating multiple elements in their design.
- **Reviewing comprehensive assessment tools and processes**, develop baseline reporting standards and procedures as well as working with government institutions and other stakeholders to model registration laws including post-conflict mortality assessments.
- **Methodological design and development work**, which should be prioritised to ensure that countries have clear guidelines in collection design, methodology, quality assurance processes, and tools to assess or improve data quality. Methodological development should also draw on other existing in-hospital sources such as mortuary guidelines and maternal death audits.
- **Building linkages with civil registration systems as a priority** through better notification of events, and using administrative and other sources of data including health notifications, burial notifications and other records advising of a death. These systems rely on better guidance on data linkage, including ethics, confidentiality and security guidelines.
- **Immediate development of mortality systems in hospitals, including review and standardization of health facility data collections.** This can be accomplished by developing comprehensive guidelines on implementation of data collection in health facilities, providing ICD training and resources (including simplified approaches), building CRVS notification and ensuring that these initiatives benefit public and private health facilities. Whilst many resources exist, the approach should focus on bringing together sources of a regional and global standard, for best country support.
- **Improving data collection for community deaths, including development of guidelines for data collection on community deaths.** Efforts should be made to increase awareness of the role of mortality data in planning and find novel ways for communities to report deaths. It was agreed that a significant body of work is required here, and should be developed cohesively.
- A critical focus on better guidance on mortality data collections and statistics in situations of **conflict or health emergency**, drawing on interregional experiences with conflict and Ebola.
- **Analysis of data**, including estimation of registration completeness, assessment of quality tools and development of reporting tools.

## Case Studies

Evidence and experience are critical to further development of mortality statistics.

- Case studies should be developed that include country CRVS and mortality statistics plans by using available evidence from countries such as Egypt, Kenya, Mozambique, Sierra Leone, Tunisia, and South Africa.
- The INDEPTH Network experience in mortality data collection in communities will be a key resource for showcasing how mortality data systems work.

## Political Commitment

Building on the Minister's call (February 2015) and the development of an African reference group for mortality statistics in Addis Ababa (July 2015):

- An Africa donor coordination meeting is scheduled to be held in November-December 2015, aimed at promoting coordinated approaches among donor agencies, and ensuring that all countries receive support.
- The *Improving Mortality Statistics in Africa – Technical Strategy 2015 – 2020* will be highlighted for endorsement at the ASSD meeting in Gabon 2015.

## African Partner Action:

In response to the evident needs demonstrated in the Cairo Workshop, WHO, UNECA and African partners, as per the Ministers Call, will:

- create a reference group to coordinate mortality statistics development work in the framework of the APAI-CRVS and the Strategy developed by Health Ministers in the WHO EMRO region;
- support the further development of the Five Year Strategy for Improvement of Mortality Statistics in Africa for presentation at ASSD;
- Follow up on the agreed outcomes and priorities of the Cairo Workshop.

## Day 1 Introduction and Objectives of the Workshop

### The Political Momentum for Improved Mortality Statistics

The momentum to strengthen mortality statistics systems aligns with the “Yamoussoukro Declaration” in February 2015 of the Third Conference of African Ministers responsible for civil registration, which identified significant challenges faced by African countries in registration of death and documentation of causes of death (CoD); specifically while responding to the Ebola epidemic faced in Western Africa. Likewise, health Ministers in the WHO Eastern Mediterranean Region have called for improvement in CRVS systems, including causes of death. Among the main challenges identified was that most countries have multiple fragmented mortality collections that fail to converge to derive usable national mortality data. There are also systemic issues propagating the current situation such as the lack of proper legislative frameworks to support mortality collections, inadequate technical guidance in this area, and inadequate capacities within countries.

As a follow up to this ministerial call, the regional civil registration and vital statistics (CRVS) secretariat at UNECA in collaboration with the World Health Organization (WHO), including African and Eastern Mediterranean regions, have led the development of a continental mortality statistics five-year strategy and the formation of a mortality reference group. The two frameworks emphasize the need for coordination, harmonization, shared resources and objectives, and

**..We call upon WHO, in collaboration with pan African organisations to intensify efforts in developing real time death registration and cause of death information systems at country level.**

implementation of systemic coordinated programmes that are country owned and country led. The priorities set for the region through these frameworks are to develop strong capacities in mortality collections and statistics; primarily through the creation of a pool of regional experts in this field, and secondly the development of relevant guidelines, manuals/handbooks for countries.

In addition to the development of the five-year strategy, a cross-regional mortality reference group was formed in August 2015 to consider how best to progress mortality statistics as an agenda within the APAI-CRVS programme and WHO EMR CRVS programs. The reference group identified that the challenges are many; including multiple fragmented and uncoordinated systems, the incorrect perception of a lack of regional expertise, and a lack of regional institutions to provide support. The regional reference group also agreed that a meeting of experts be held, at WHO EMRO’s invitation in Cairo, Egypt. The purpose of the meeting was to gather experts across these regions in mortality statistics collections together to:

- **Collaborate on new technical guidance** to be provided to countries for designing better mortality statistics systems; and
- **Develop a pool of available experts** to deploy to countries to support technical improvement and results in mortality data collections, especially for death registration, hospital deaths and integrating systems for community deaths.

# Designing Better Mortality Data Systems

## Current Status of the CRVS in Africa

There have been a number of initiatives to improve CRVS systems in Africa during the recent past. However, these initiatives were not successful for several reasons such as lack of political commitment, the adoption of adhoc project-based approaches, poor legislative frameworks, inadequate capacity in countries, and lack of coordination among the relevant institutions within government (e.g. health, statistics and civil registration authorities) and also among donor agencies.

The existing regional momentum for CRVS builds on the lessons learnt from these past initiatives, primarily through promoting systemic coordinated and harmonized approaches, capacity building, strengthening political commitment, promoting collaboration between key stakeholders and providing the required technical and financial support to facilitate the implementation of country programmes. It especially focusses on the success of other statistical programs in developing a pool of regional experts able to provide consultancy advice and technical support to African initiatives.

The African CRVS initiative is backed by significant political commitment and support through the conference of African ministers responsible for civil registration; a biennial gathering that has provided policy guidance and directives for CRVS improvement in Africa. As mandated by the ministerial forum, the initiative is steered by the United Nations Economic Commission for Africa (UNECA) as the secretariat, supported by a group of United Nations agencies, pan African organizations and non-governmental organizations that form the regional CRVS core group. The approach adopted seeks to promote coordination and secondly to harness the synergies derived from the technical competencies of these different organizations.

Through the regional initiative, 20 African countries have completed rigorous assessments of their CRVS systems, while eight are preparing or are in the process of conducting the assessments. The assessments have been critical in laying the foundation for prioritization of areas of improvement, specifically through identification of challenges that have been clogging the systems over the years.

Accessibility, costs of registration, inappropriate use of technology, colonial laws that are inconsistent with contemporary practice, poor business processes, and capacity issues have been identified to be the most outstanding challenges affecting CRVS systems for most countries.

## Key discussion points and reflections

- Recognizing that immunization coverage rates are close to universal in most countries, the use of community health workers (CHWs) as notifiers of the occurrence and key characteristics of vital events in order to improve registration completeness becomes very important. Nevertheless, there is a need to keep in mind that CHWs have other competing responsibilities. Other community level cadres may be able to participate in the notification of vital events, particularly deaths, such as burial and funeral authorities, religious institutions.
- Coordination challenges exist between the ministries involved in CRVS operations (mainly the registration, health and statistics departments), which should be addressed. As part of strengthening mortality statistics and CRVS systems, a functional and high-level coordination committee should be established.
- CoD data recorded through verbal autopsy (VA) are not recognized legally. This limits the use of the information collected for legal purposes but the cause-specific mortality fractions generated through VA are important inputs to the mortality statistics system.
- Priority should focus on providing guidance to countries to modify registration laws to make them conducive to the development of better civil registration systems.
- There is a need to promote documentation of best practices and knowledge sharing among countries.

- Rigorous training and technical support is required for countries to achieve the desired outcomes in terms of improved availability and quality of mortality statistics.

### Technical Strategy for Improving Mortality Statistics

The regional strategy for improvement of mortality statistics is a critical requirement for the continent in the management of mortality data at country level as well as in responding timely to the global development agenda. The strategy recognizes the existence of fragmented mortality collections in most African countries, which if integrated could yield significant improvements in mortality statistics. The rationale set by the strategy is to use the available sources of mortality data to complement the collections made by the civil registration system (recognizing the high levels of incompleteness) and thereby strengthening CRVS as the most ideal source and archive for mortality data.

The strategy is based on four building blocks: (i) country expertise and regional expertise; (ii) scaled and integrated technical projects – projects on death registration that can demonstrate scalability and sustainability, projects on CoD in hospital and non-institutional events, partnerships with academic institutions; (iii) norms, standards and guidance; and (iv) knowledge development and sharing.

Some of the experiences or lessons learnt by the Republic of Sierra Leone following the Ebola outbreak are that:

- The country has a very weak death registration and CoD information system.
- Following the epidemic, death registration was taken over by the Red Cross. This sidelined the responsibilities of the ministry responsible for civil registration. Deaths registered by the Red Cross were not captured in government records.
- All deaths occurring within that period were associated with Ebola due to lack of proper means of establishing CoD.
- CHWs played a critical role in capturing of deaths occurring by reporting death occurrences in the communities to the nearest district hospital.
- Coordination with cemeteries and institutions conducting burial is critical in ensuring that all deaths are registered and CoD determined prior to burial.

### Other Discussion (focusing on country experiences)

- Although it is ideal for demographic surveillance sites to be linked to the civil registration system, there is a need to develop methodology and harvest experiences on how this can be done.
- National Strategies for Statistical Development (NSDSs) must embed mortality statistics from civil registration. The development of the third generation of NSDSs should take this into consideration.
- An Africa donor coordination meeting is scheduled to be held in November-December 2015, aimed at promoting coordinated approaches among donor agencies, and ensuring that all countries receive support.
- There is a great need for contextualized research (based on experiences of African countries) and innovations geared towards systems improvement. Such research should be reflected in the strategy document and will be useful in strengthening the case for the strategies proposed.
- Guidance notes on mortality statistics improvement across the three goals outlined by the strategy should be developed. The notes should be based on practices that have worked well in countries.
- The contribution of maternal death audits towards mortality statistics improvement should be incorporated into the strategy.
- The strategy should have a stronger focus on the development of routine approaches for VA for community deaths as part of the civil registration process.

- The strategy should underline the importance of a comprehensive legal framework in improving death registration and CoD information. The need for review of legal frameworks should therefore be explicitly mentioned.
- Recognizing that all countries are at different levels of developing their systems, the strategy should categorize countries by levels of development (e.g. weak systems; strong systems) and propose strategies for improvement based on the level of development, drawing on the WHO 2014 report on strengthening mortality statistics systems.
- Incentives matter: there are significant incentives for birth registration, such as access to health and education services, but hardly any for registering deaths. There should be more thinking on how to incentivize registration of deaths across the continent. For example:
  - Enforcing public health legislation and regulations on the safe disposal of bodies;
  - Monitoring and controlling the cemeteries (beginning with urban areas);
  - Promoting use of CR records for Inheritance of decedent's estates;
  - Claiming social insurance benefits, such as funeral expenses, spousal benefits, pensions etc.
- There is lack of baseline data to justify the goals outlined and the number of countries (20) targeted by the strategy. In this regard, the goals should be revised to 100% and each country should define its expected levels of performance and timelines.
- An activity plan that outlines specific actions, key milestones, and outcomes (including how they will be measured) should be developed. There should be clarity on what the achievements should be in 2020 also taking into consideration that different countries are at different stages of development in terms of their systems. There is also a need for standardization and harmonization of methods.
- The strategy should include a goal on the use of data generated from these systems, and promote the analysis of incomplete or poor data as a primary step towards improvement.
- The strategy should include a comprehensive monitoring and evaluation framework.

#### **General comments**

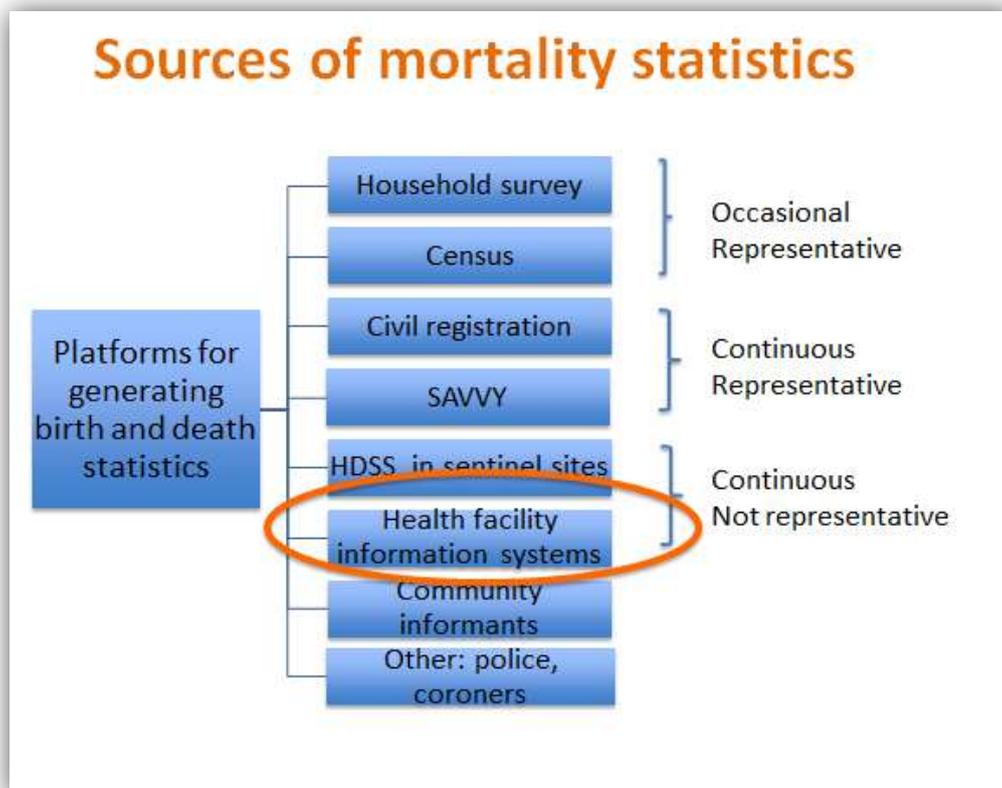
- It is very important for the regions to collaborate especially in the production of public goods. This should alleviate duplication of efforts and maximize on the resources available.
- There is an increasing need for the creation of health statisticians in all countries

## Mapping Mortality Data Sources and Needs

### Emerging Need: Designing Mortality Systems

In November 2014, discussions among advisory group members focused on efforts to improve mortality data focused on designing better mortality systems by taking into account the availability of multiple sources of data. Another issue in the discussions was the recognition that multiple sources can be both a challenge and an opportunity.

Globally, most countries do not report mortality data to WHO particularly data on CoD. Nevertheless, there has been a significant evolution in mortality data collection though not in a cohesive way. Surveys and censuses; surveillance systems; CRVS; hospital deaths and ICD; and other collections still remain the common sources of existing mortality data.



Some of the methods of data collection (e.g. surveillance data in sentinel sites, HDSS) lack representativeness whereas other efforts such as the ICD are intricate with a lot of classification complexities thereby rendering production of mortality data challenging.

One key question is: **Where are we heading to with all the available data and fragmented systems?** To answer this question, current efforts should focus on implementing one cohesive system, drawing on multiple sources, that is well designed and sufficient to meet the needs of all countries and partners. This will ensure that data are available for the SDGs, monitoring outbreaks, building and strengthening health systems, health financing, population statistics, and supporting governance and administration.

Multiple systems are a reality and the targets set in the technical strategy for mortality data improvement in Africa are not too ambitious but demonstrate that something can be done to improve mortality data. All the health goals in the SDGs rely on CRVS despite the risks associated with multiple collections. The question is whether this is possible? Half of the information that can be generated by revamping the mortality systems is better than nothing. We need to do something. There is high and serious commitment to improve mortality in Africa and the Eastern Mediterranean region.

Multiple systems are also an opportunity and need to develop an integrative approach by developing a CRVS platform, providing innovation, developing health mortality statistics, and optimizing data from multiple sources.

The advisory group meeting in November 2014, among other things, recommended reviewing and improving mortality data collection methodology through careful enumeration of all events, drawing and integrating data from multiple sources, developing novel approaches to collect data on community deaths, and improving and making such systems sustainable.

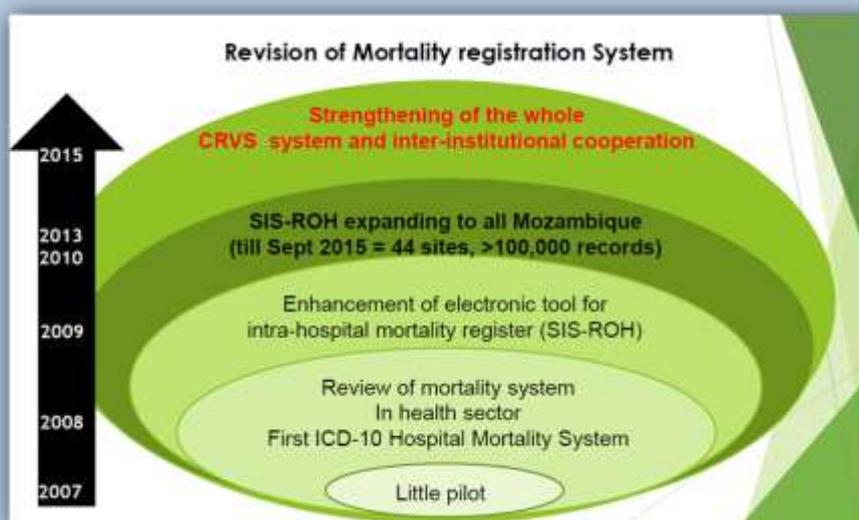
Mapping the existing mortality system is the first step in designing a better system. We need to understand, *inter alia*, what mortality data are available in different countries (e.g. deaths and births). For example, understanding the process of death registration through funeral records, burial records, and ultimately death registration. Other sources such as community death recording or police records can be examined. A combination of these methods should be linked together in order to have a better understanding of mortality data collection in a country.

### Challenges of Multiple Community Data Collection: The Case of Mozambique

Population-based surveys are the main sources of mortality data in Mozambique. The Durban Meeting of African Ministers in 2011 committed to improving CRVS in Africa and Mozambique is implementing a number of activities to respond to the Ministerial call. With an estimated population of 25 million in 2014, Mozambique was the first African country to conduct a comprehensive CRVS assessment in 2013. As of September 2015, 9% of deaths were reported by CoD in Mozambique whereas 14% of deaths are registered.

Although the CRVS in Mozambique is fragmented, current operation plans are aiming at consolidating it. Mozambique has also adopted the ICD-10 as a national standard for the selection and classification of CoD. Training of health staff is one of the main components of the operational strategy as well as the development of a costed operation plan.

Challenges experienced by Mozambique include data sources that are not linked, low coverage of community death registration, and limited availability of ICT. Mozambique has a plan to ensure that the health facility mortality data and the electronic CRVS are linked as well as creation of a National Health Observatory. The CRVS plan also includes revision of legislation, approval of new and modified forms to ensure that data are reliable and address national needs.



## Mapping and Integrating Mortality Data Sources: The Case of Kenya

The 2012 Constitution of Kenya states that every citizen is entitled to registration documents and the Registration Bill of 2012 consolidates all registration documents and processes. Mortality information comes from deaths occurring inside health facilities and those occurring outside the health facilities. However, information is not known for deaths occurring outside the health facility.

Gaps exist within the current CRVS as evidenced by lack of linkages with institutions such as the Ministry of Health, Civil Registration Services, and the National Bureau of Statistics. This leads to low death registration coverage at the national level such as the estimated 45% death registration between 2010 and 2015. As expected, death registration in selected areas such as the capital city, Nairobi, is higher than in the other provinces.

Key challenges with the CRVS in Kenya include: (1) lack of complete enumeration of all deaths occurring even within the health facilities; (2) not all events are captured and some of the tools used are not ICD 10 compliant; and (3) unethical practices particularly those related to HIV/AIDS in certifying cause of death. For community events, reporting is incomplete and not consistent with the ICD 10 standards. The Monitoring and Evaluation system is also weak. Another major challenge is the low demand and utilization of vital statistics.



Not all health facilities report their data through the District Health Information System (DHIS) and have inadequate infrastructure for electronic reporting. Surveys that have been deployed are periodic and do not provide indicators at the sub national population level. Not only do censuses take longer to be conducted than surveys but they are also often interfered by politics and generate limited mortality indicators.

While health and demographic surveillance systems (HDSS) sites are useful in understanding mortality dynamics at the sub national population level, they have limited coverage at the national level and there is limited willingness to share data. Morgues and funeral homes have no clear reporting systems and the existence of multiple sources of mortality data is characterized by systems that operate in silos and lack stakeholder communication.

Despite these challenges, Kenya has accomplished a number of activities related to improvement in CRVS. A national coordination mechanism has been established through a technical working group and this has been enhanced through development of a national strategic plan, national monitoring and evaluation plan, establishment of national population register (with CRVS as main contributor), development of case based tool on capturing mortality data, review of medical certificate to be compliant with ICD 10, and analysis of CoD, among others.

Ongoing efforts in Kenya include review of the legal framework, scale up of Monitoring of Vital Events by using Information Technologies (MOVE IT); improve community death reporting through VA; publication of annual vital statistics report; ICD-10 training; resource mobilization; maternal and child health strategy scale up through a memorandum of understanding (MOU) with the Ministry of Health.

Planned activities in Kenya include development of an MOU on data sharing with HDSS sites; mainstreaming ICD 10 training curriculum in medical schools; and retrospective mortality trend analysis with support from the Global Fund.

## **Key discussion points on Mozambique and Kenya case studies**

### ***Technical support***

- Mozambique asked for technical support during the CRVS assessment and it is clear that many countries will seek similar support. After the CRVS assessment and plans, there will be huge demand on short-term and long-term technical support.
- Other institutions (e.g. universities and other research institutions) are critical in ensuring improvement and sustainability of CRVS.
- Kenya is piloting VA tool to address deaths that occur outside the health facility. Within the community, maternal death reviews are conducted for each maternal death reported to establish the circumstances around the maternal death.
- There is also a need to unpack what is meant by “support” considering that there is lack of literature on country experiences and how to move from the past to the future. We need to build up case studies that can be used in handbooks.
  - Principles and recommendations are often developed and later operationalized but have no specific examples from countries. The most important strategy is to ensure that we have a platform to share information.
- The WHO Regional Office for the Eastern Mediterranean (EMRO) comprehensive assessments demonstrated that using available social capital in each of the countries is ideal. Another strategy is the control of the burial permits at the cemetery (no burial without registration of death, or VA, or similar initiatives).

### ***Coordination, TWGs***

- Technical Working Groups (TWGs) are ideal to mobilize stakeholders and ensure cohesiveness in approaches to improve mortality. TWG should also be proactive in approaching donors on their needs and create opportunities for all stakeholders to know each other, discuss their successes and challenges, and have a common understanding and goal.
- Convening a TWG in Kenya: The first step was to develop the ToR for the TWG followed by identification of the Chair for the TWG who was an individual outside the Ministry. Stakeholder mapping was completed with strategic areas for potential support. A desk officer was identified for each partner or stakeholder. Current efforts are being made to cascade the TWG to the sub regions. The stakeholders also assist in bringing technical experts for each of the strategic area.
- The TWG has a data analysis task force and included expertise on mortality analysis such as institutions and other individuals.

### ***Training and capacity development***

- Training curriculum is critical in strategies to improve mortality data.
- The strategy or training modules should focus on main issues that will be shifters of mortality improvement.
- Involving medical institutions in training on ICD 10 has had positive impact than just bringing a pool of trainees together

### ***Incentives for mortality reporting***

- The low percentage (9%) of deaths with CoD assigned is worrisome in Mozambique considering the efforts that have been made in the recent past to improve death registration. To address some of these challenges, Mozambique is rolling out the DHIS database across all facilities.

### ***Methodology and Technical Resources***

- We need standards that are very easy to implement in order to improve mortality data collection and processing systems.
- Where we want to go is clear. That is, to have every death registered. But we need to know where we are before deciding where we want to go. This can be achieved by understanding the current business process and thinking of where we want to go next.

- Methodology is needed for mapping deaths from multiple sources (e.g. deaths from Ministry of Interior records and those from the hospital records).
- Interventions should be deployed to improve mortality based on existing challenges of mortality data. These interventions should be prioritized to ensure that interventions target the key challenge (e.g. low registration of deaths).
- There is a need for methodology to be developed to improve mortality data collection systems.
- There is a need for tools to be developed for use by technical experts when providing support to countries.
- If legal frameworks are a key challenge, we need to ensure that as experts, we need to establish the minimum prescription of the legal framework that can improve mortality data collection.
- A number of things need to be done at the country level. The mortality handbook or guidelines will be a starting point to meet the needs of countries

### ***Improving analytical capacities***

- Need to think of strategies to improve mortality data collection beyond statistical and demographic techniques of adjusting data. For example, if we know that age reporting is problematic, what can we do to address this apart from using adjustment methods?

### ***Demand side***

- To deal with low utilization and demand for mortality data in Kenya, TWG members have directed meetings or presentations to institutions and other agencies to generate their interest in mortality data.

## **CRVS Planning in Mozambique**

Delegates from Mozambique shared their experience in undertaking CRVS comprehensive assessment and the development of a national operational plan. The assessment began with the identification of focal points from different key stakeholder institutions. The rationale was to ensure participation of all relevant sectors, ownership of the plan, and to facilitate better coordination between the involved sectors during and after the assessment. A technical working group composed of representatives from these stakeholder institutions was formed. The assessment and planning process derived significant support from the political leaders and primarily, the heads of the key institutions were engaged in the process. Some of the key lessons learnt from the exercise include:

- Use of the comprehensive assessment tools developed by the regional CRVS core group is critical in ensuring a holistic review of the system.
- There is a need to set aside adequate time for preparation and training. The two months allocated for the assessment in Mozambique were inadequate.
- There is a need to clearly define roles and responsibilities of all persons and institutions involved before commencing the assignment.
- The assessment in Mozambique covered three provinces, which didn't necessarily represent the situation at the national level. Setting a wider scope for the exercise is critical.
- Political commitment and support is paramount for the success of the entire exercise.



Ongoing activities include the development of an electronic civil registration database and linkage of the database with national identification numbers. Mozambique has also developed a CRVS call centre that generates automated short text messages to update the public on the status of registration; reviewed CRVS forms to meet national needs for vital statistics production; and developed a common national CRVS plan for the Ministry of Health and the Ministry of Justice

### **Key discussion points**

- There is a need for UNECA to conduct a review and recommend the ideal duration for undertaking the assessment and planning processes.
- There is also a need to review the existing country plans and ensure that they meet the required standards of quality and comprehensiveness.
- Country plans and investment proposals should be shared with other countries for learning purposes.
- The creation of strong coordination frameworks among UN agencies and government ministries is critical to the success of any CRVS programme.
- There is a need to link the outcomes of the assessment with the regional mortality strategy being developed.

## Day 2 Evolution in Community Mortality Collections

Demographic and health surveys and censuses have been the most commonly used sources of birth and death data in most countries. The major strength of these is their national representativeness and high quality of data collection and analysis. Important weaknesses are that they do not generate data at subnational administrative levels and are occasional in nature, not generating a continuous stream of mortality data. Moreover, sample size considerations preclude their use for generating reliable data on causes of death. CRVS systems have important advantages in that they provide total counts of events, on a continuous basis and for lowest administrative levels.

Sources of cause of death data and statistics include the censuses with follow-up VA exercises (for example as conducted in Mozambique), civil registration – drawing data from the health sector, HDSS sites (through SAVVYs), and health facilities, among others.

Recognizing that most events of death in Africa occur outside health facilities, the role of community level structures in reporting deaths and documentation of CoD becomes pertinent. Community reporting is largely challenged by the definition of who does the reporting. Reliance on CHWs is constrained by the fact that they are involved in other equally engaging responsibilities and also that given the nature of their work, they would prefer to report events of births rather than deaths. Including reporting of deaths within the job description of CHWs is likely to improve their level of reporting on both births and deaths.

**There was significant discussion on the role and future integration of HDSS sites into a functioning mortality statistics system:**

- HDSS sites are a potential important source of mortality and CoD data particularly in largely populated countries where starting up and scaling the civil registration system may be difficult.
- HDSS sites that track births and deaths in a local area and conduct verbal autopsies to identify probable causes of death are a potential important source of mortality and CoD data but do not generate nationally representative data. HDSS sites can help build capacities for registration and could be positioned as a first step towards establishing a fully functioning civil registration system if they can be linked to local civil registration systems but there is currently little experience in doing so
- It is feasible to position HDSS sites as a first step towards establishing a fully functioning civil registration system, by drawing the sampling frame from civil registration districts and linking the two through ensuring that actual (legally backed) registrations are conducted
- Advantages of HDSS sites in building civil registration systems include that they:
  - Collect far much more information than civil registration hence providing an environment for testing of methods, and for learning;
  - Provide an independent source of data useful in checking the quality and completeness of civil registration records;
  - The human resources used in these sites are already trained hence no new investments in staff are needed.

- Technical issues in the application of HDSS sites to support civil registration include the selection of samples and computation of the sample sizes.
- A study on record linkage conducted in South Africa showed that there are no significant differences in distribution of characteristics of the two data sources (HDSS (with SAVVY) and the CR system).
- Sustainability of HDSS sites is required if the sites are to support civil registration systems. In addition, the sites should be able to provide data that are representative at the national level.
- There are potential risks in investing in HDSS sites as a support mechanism to civil registration systems. For example, the sites are likely to create competition for resources with the mainstream civil registration system and also that the sites are resource intensive and are therefore largely unsustainable.
- While there is currently no evidence of using HDSS sites as a stepping-stone to building civil registration systems, they can be of immediate utility in the testing of methods, checking of data quality and building local data collection and analytical capacities.
- In the wake of the SDGs, there should be clear communication to donors on the lack of evidence that HDSS sites (upon expansion) would lead to any substantive improvements in civil registration systems.

### Key discussion points

- Considerations should be given to alternative persons that can replace CHWs as informants for events of death.
- The lack of training among CHWs yields problems in the quality of the data produced through such collections. Monitoring and evaluation becomes critical in improving the quality of reporting.
- Studies on practices in community reporting conducted in Ethiopia, Malawi, and Mali revealed that accuracy of the reports varies widely by country and the type of event (birth or death). The study found that it is difficult for health workers to report on deaths as compared to births. Mali provides a good example that the use of CHWs can be successful, with innovations required in monitoring.
- More research should be conducted to define appropriate strategies for community level reporting and building the relevant linkages to civil registration systems.
- Sample registration systems with verbal autopsy (SAVVY) offer a platform for generating nationally representative particularly in largely populated countries where starting up and scaling the civil registration system may be difficult. It is important that such sample systems be introduced not as stand-alone systems but as integral to the CRVS system. To foster this, the sampling frame for the selection of sites should be drawn from civil registration districts and efforts should be made to ensure that all vital events identified are linked to the official civil registration system. Examples of such an approach are currently under way in Tanzania and Zambia.
- Considerations should be made on alternative persons that can replace CHWs as informants for events of death.
- The lack of training among CHWs yields problems in the quality of the data produced through such collections. Monitoring and evaluation becomes critical in improving the quality of reporting.
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- More research should be conducted to define appropriate strategies for community level reporting and building the relevant linkages to civil registration systems.
- Resources for development of CRVS systems should not be diverted to development of HDSS sites.

- VA is an imperfect method but the only way to collect information on CoD where the physician is not available. It can also be used as an adjunct to the cause of death determined using medical certification, for example in confidential enquiries. It is also used to verify routine civil registration.
- The application of VA in determining causes of death is enormously a staff intensive activity. It costs around US\$23 per case depending on the country.
- The method can therefore not be applied on every event of death; a representative sample frame is required. The use of VA should be accompanied by careful attention to the local sociocultural environment and acceptability, including informed consent.
- VA should be accompanied by 2-3 interviews per month ensure that the skills of VA interviewers are maintained.
- A consent form that accompanies the tool is very important in clarifying to the relatives that they would not be informed of the CoD.
- Given the lack of physical addresses or street names in sub Saharan Africa, there is a need to advance the software to include geo-referenced coordinates for locations. This proposal should be forwarded to the VA working group.

## The Challenge of Scale and Design: Selected Country Experiences

### The Challenge of Scale Up

Ensuring that all deaths are registered, focusing on strengthening hospital data and then community deaths should be the key principles of design and scale up of mortality systems. Working for a representative community deaths system with deaths notified and probable CoD determined is one of the key goals as part of the mortality improvement system.

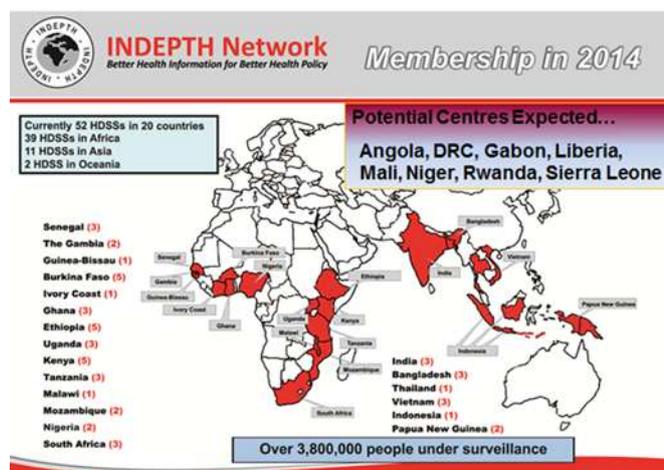
### Moving surveillance forward with CRVS: The INDEPTH Network View

The INDEPTH Network presented a new acronym “CHESS” as part of the CRVS improvement agenda. The acronym stands for “Comprehensive Health and Epidemiological Surveillance System.

The INDEPTH Network HDSS sites have substantial expertise to address some of the current needs and challenges to improve mortality data. A number of HDSS sites have been collecting longitudinal data for more than a decade. As of September 2015, the INDEPTH Network had over 4 million people under surveillance across sites run by its member countries, with a total of 45 centres operating 52 HDSS sites.

A strategy to build a stable CRVS for death registration could start with sentinel registration followed by sample registration and finally full registration. Despite the successes associated with HDSS operations, funding challenges are enormous in implementing HDSS sites and scaling up.

Representativeness of sites is also another challenge since the sites operate in selected populations specifically chosen to meet specific criteria. The INDEPTH Network is supporting initiatives for developing the CRVS and considers SAVVY as complementing the CRVS system. The core surveillance system is expensive and some sites are closing down due to lack of funding.



### Death registration in Egypt

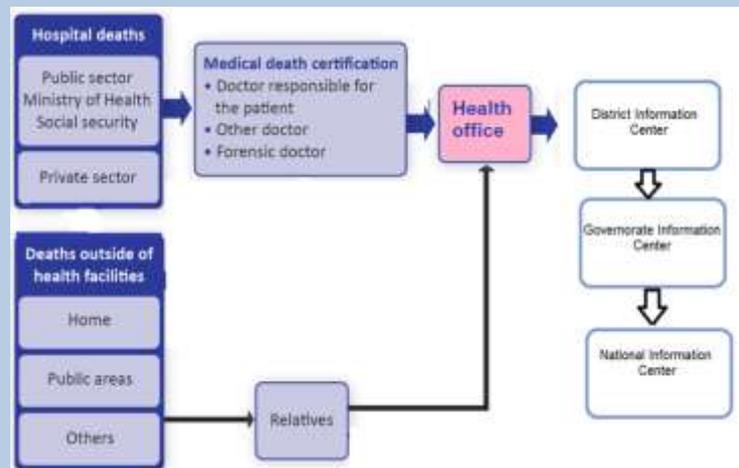
Legal framework for civil registration: There is a law on civil registration that applies to every individual and agency. The burial is considered as a way to honor the dead and families must notify authorities before burial. This is an enabling factor to improve death registration coverage.

There are 4,500 health offices at the local level responsible for registering births and deaths. Events at the community and health facility level are reported to the district health office then to the governorate and finally to the Ministry of Health which then reports to the Central Agency for the Public Mobilization and Statistics.

The civil registration coverage is almost universal (98%) in Egypt but suffers from lack of awareness of the importance of CRVS and that fact that VAs are not used. The system also lacks coordination among its stakeholders; lacks comprehensive electronic systems; and majority of staffs are not highly qualified. Less reliable CoD represent 48% of registered deaths.

Egypt has established a committee to oversee implementation of strategies to achieve universal coverage and improve the quality of mortality data. To achieve this, VAs are being used to verify cause of deaths, use of ICD 10 full list, death registration forms are being reviewed, and training on ICD 10 and for VAs. Interventions to increase awareness and importance of CRVS are being implemented. The automated system has a verification system and real time notification to the central server as well as rejection of entries for CoD that are inconsistent with age and sex, among other things.

Efforts towards universal coverage of events and improvement in mortality systems include speeding up automation of health offices and to use VAs as routine method to establish cause of deaths at the community level. Training of trainers on ANACOD has been planned for all governorates staff. There is a proposal to include ICD 10 in medical school and nursing college training modules.



### CDC Civil Registration Activities in Africa

A stepwise approach and scaling up of CRVS activities in Africa has been proven to work. Use of mobile technology where applicable should be encouraged and the involvement of government officials and subject matter experts.

CDC country projects include Kenya, Malawi, Morocco, Zambia, Sierra Leone (under development) and South Africa. In Zambia a SAVVY Project was conducted aimed at enhancing the birth and death registration system with a sample of 30,000 households and focusing on birth, death, and VA. Causes of death coded with ICD 10 and the project is expected to start early 2016. The SAVVY is being implemented by the civil registration authorities in collaboration with other institutions.

## Day 3 Designing Better Hospital Collections

The role of hospitals in the notification of births and deaths and in the collection of CoD information should be advocated for especially given that these institutions have the expertise to undertake this work. WHO/World Bank's targets for hospital reporting are: "80% of deaths in hospitals have causes of death reliably determined and officially certified in real time". These, however, are global targets. Countries are encouraged to set their own targets and to undertake regular monitoring towards the realization of the same. Problems of hospital collections in CoD reporting are diverse including:

- The lack of reporting by private hospitals.
- The use of paper based systems in most hospitals which makes it very difficult to compile complete records.
- Poor quality of medical records which make it difficult to compile good quality CoD information.
- In many cases, physicians are inadequately trained in death certification and therefore often not well aware of the importance of proper recording.
- Lack of sufficient physicians and also poorly distributed physicians (often concentrated in the capital city) constraints collections from hospitals in the rural areas.
- In many countries, the responsibility of registration is left with the family. Having the health facilities as informants is an important strategy to improving registration coverage.

### **Key discussion points**

- To improve hospital collections, it is important to clearly define hospital deaths. Such definition should address (i) the inclusion of deaths occurring 30 days after discharge; and (ii) the handling of dead-on-arrival cases. Physicians are often reluctant to complete CoD for certificates for such events.
- There is a need for comprehensive guidelines and training on recording of causes of death within health facilities.
- Recognizing that in many settings most physicians are located in urban areas, improvements in CoD reporting may be achieved through identifying alternative medical personnel who can support this function. In Kenya for instance, clinical officers are legally allowed to certify deaths.
- Challenges experienced in Kenya include that physicians find the transfer of CoD information to the register of death as extra work. The information collected is also often not ICD compliant.
- It is important to enhance monitoring and evaluation of health facilities collections.
- In cases of deaths occurring in urban areas, improvements can be made by enforcing public health legislation regarding the disposal of bodies. Burial permits should be issued only when a medical certificate of death including CoD has been issued.
- The laws should also obligate all private hospitals to certify deaths and to report on causes of death to the relevant institutions.

### **International Classification of Disease (ICD)**

Health facilities are key to improved cause of death data because medical physicians are the only ones legally allowed to issue CoD certificates. However, in most African countries, people die at home and hence hospital data only represent a small fraction of deaths in a country, and are hence not representative. However, it is important to drive the case for credible hospital mortality data.

- Implementation of national laws on certification death before burial is oftentimes constrained since in most developing countries individuals may have to travel long distances to find a physician or the legally designated personnel to certify the CoD.
- Consideration should be given to extending the cadres of trained health care workers empowered to issue medical certificates of cause of death. However, it is important that a caveat is included on the forms indicating that a physician did not issue the diagnosis.
- Routine training of physicians on the importance of completing CoD information accurately is important.

- The most critical consideration in ICD coding is the quality of data derived from the process. Pre-service training (for students) and in-service training is an important requirement.
- Particularities for training in ICD in the African context include standardizing training manuals and procedures, making ICD copies available (hard copies), including representatives for civil registration authorities, including coders for certification training and including physicians for coding training.
- Conducting a needs assessment among the trainees prior to the training is pertinent to the success of the training programme.

#### **Country Experiences:**

Tunisia has been analyzing annual statistics on CoD since 1991. Upon registration of death and acquisition of a death certificate, members of the public are required to seek permission to bury the deceased from the municipal office.

- In 2014 Tunisia recorded 93% of all deaths. The National Institute of Public Health (NIPH) conducts coding of CoD. The coding processes are constrained by the fact that only less than half of deaths are reported to NIPH, and that some doctors do not complete forms accurately or in the required format.
- Tunisia has initiated a mandatory training programme for medical students on how to complete certificates of death and is also planning training workshops for physicians.
- There is a need for WHO to develop a French version of the academic training manual on death certification.

South Africa has moved from the use of ACME to IRIS. Causes of death are coded manually and also derived automatically. IRIS in South Africa is used in code and text entry modes. Through the use of this software, South Africa has significantly reduced data processing backlog from two years to one year. In South Africa, small inconsistencies are identified while running ACME against the results derived from IRIS. South Africa also lacks local technical support in the application of IRIS.

Mozambique has revised civil registration forms to a statistically friendly format and launched an electronic tool for data capturing which is yet to be rolled out nationwide. A stakeholder-working group has been formed known as GITEV responsible for policy oversight on CRVS, including negotiation with all CRVS donors. They have published three national mortality reports to date.

- Success factors in Mozambique include the appropriate application of technology as a tool to achieve the identified goals, stakeholder support especially from the Ministry of Health, creation of high level working group - bringing together different stakeholders, and strong quality assurance mechanisms.
- Mozambique has significantly improved filing for civil registration records. Next steps include promoting interoperability and integration of the civil registration system with other relevant systems and plans to expand the automated system to all other health facilities at the national level.

## The Role of Surveys and Censuses

Surveys have been instrumental in providing all-cause mortality data in many countries, especially for under five mortality, but somewhat less successfully for adult and cause-specific mortality (e.g. maternal mortality). A comprehensive list of surveys in developing countries is available at [www.ihnsn.org/home](http://www.ihnsn.org/home). Survey mortality modules often include the household module (for orphanhood questions) and the individual modules for questions related to the sisterhood method.

The disadvantages of surveys, however, relate to their periodicity, recall bias on information such as age and time of the event, incompleteness of data and sample sizes that often do not allow disaggregation of data at the lower administrative level. Long questionnaires also often contribute to incompleteness of data due to respondent fatigue.

Maternal mortality estimates currently are based on the application of sibling survival methods in surveys and not VA data. Most of the data provided by the UN Inter Agency Group on Mortality Estimation come from surveys. As part of efforts to improve death registration coverage and quality of mortality data, there is a need for more capacity building skills on data quality assessment, trend analysis, reliability measures, and use of software such as MORTPAK and CMRJack.

For the foreseeable future, surveys will remain the main source of mortality data in many countries. Paperless technology in data collection and processing will minimize survey costs. Electronic VA processing will grow and minimize implementation cost.

### Mortality Statistics from Censuses: Key Issues for Consideration

Principles and recommendations for modern census taking recommend data linkages and confidentiality, collection of priority topics such as date of birth of last child born alive, household deaths in the past 12 months, maternal and paternal orphanhood, and births in past 12 months. Some also include a follow-on VA study as was done in Mozambique.

For household deaths, the interest is to include CoD question such as on pregnancy-related deaths, or violence or accidents. However, experience with data on maternal mortality from the census has shown the need for data analysis and adjustment. Not all countries are collecting data on the recommended topics. Most countries are collecting data on births in last 12 months and household deaths in past 12 months.

The challenge is that whilst a lot of data are available for African countries after the 2010 round of censuses, limited analyses have been done and the number of surveys being conducted is increasing. To address some of these challenges, there is a need to make special efforts to increase mortality analyses; develop clear roadmap for analysis of mortality data and dissemination; and make more efforts to have more equitable distribution of surveys in Africa.

## Collection of Mortality Data in Conflict and Post-Conflict Settings

Death registration in conflict and post-conflict settings is a politically sensitive issue since the data may be interpreted differently depending on local circumstances and the response by the international community. Three main methods for conflict mortality estimation: household surveys, passive surveillance, and indirect demographic methods capture-recapture methods. Despite the availability of these methods, limited data exist on mortality of conflict populations. Recent studies on mortality in conflict settings such as Syria and Yemen have shown that the demographic and epidemiological profiles as well as the nature of the conflict are evolving. Important data in conflict and post conflict settings are being collected and need better coordination and collaboration to ensure that the data are of high quality and reflect the reality. However, these data come with heightened privacy and confidentiality challenges.

### General comments

- We need to ensure that while developing CRVS, surveys and initiatives such as SAVVY provide monitoring and benchmarking indicators. For example, we use the CRVS to measure coverage against census results.
- Censuses are useful as an additional data source for mortality estimation, but there is a lot of work to make the estimates reliable. We need to maximize the census data by getting more information on the deaths that are identified, e.g. where did they occur? Was it in hospitals or at home? Was a formal certificate of death issued? Was the death registered with the civil registration authorities?
- There is a need to invest more on censuses and ensure that all questions on mortality are asked to make it more relevant. Nevertheless, there is a limitation on the number of questions that can be included in the census. Notwithstanding this, we should encourage analysis of the existing census data that are very expensive to collect.
- We should mobilize support for all countries to have an equal distribution of surveys in Africa. Some countries have multiple surveys whereas others have no surveys.
- There is a need to include a clear statement on the strategy for developing CRVS in conflict countries.
- The experts at this meeting and those who were not able to attend should be prepared to provide support to countries on mortality data collection and processing.

## Resilient Mortality Systems in Africa

*'First, resilient health systems are aware.... Awareness needs strategic health information systems and epidemiological surveillance networks that can report on both the status of the system and impending health threats in real time, allowing predictive modelling. Information can come from traditional (facilities, audits, surveillance, population surveys), and less traditional sources (social media, health worker call line, satisfaction surveys). This information should in turn inform planning, including tabletop exercises to simulate the logistics of a response to crisis. (Kruk et al 'What is a resilient health system? Lessons from Ebola' Lancet 2015; 385: 1910–12)*

Drawing on lessons from Ebola in West Africa and the need to provide real time data, mortality systems should be developed to cater for emergency needs and not only a system that cannot cope with emergency periods. Such systems require strong coordination and partnership from government, community leaders, and other development partners.

## Collection of Mortality Data in Conflict and Post-Conflict Settings

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Aside from the issues of mortality data availability and quality, it is important to consider issues such as the maintenance of registration options and facilities during conflicts and the need to ensure safe storage and protection of registration archives during the conflict.

## Day 4 Data Analysis, Quality Assurance, and Archival

### Using the data: concepts, challenges, quality

Birth registration coverage is often close to universal compared with death registration coverage. In addition, trends reveal that regions with high levels of mortality are often associated with high levels of incomplete registration.

- Most countries hardly use CRVS data for mortality estimation. Failure in civil registration systems during the recent past has led to reliance on other sources of mortality data such as population censuses and periodic surveys.
- **It is recommended that every country should produce vital statistics report irrespective of the level of completeness of its civil registration system. The production of such reports is critical in providing the basis for advocating for further development of the systems.**
- While recognizing the importance of population censuses and surveys in assessing quality of civil registration data, it is important for countries to take adequate measures to guide the design of future population and housing censuses in relation to the development of civil registration systems.
- The data demands of the SDGs are likely to lead into increased interest in survey programmes. There is a need to think through and guide how such thinking will impact on the development of civil registration systems particularly in view of the resources for investment.
- There is a need to incorporate training on civil registration into the academic curriculum of demographic training institutions.

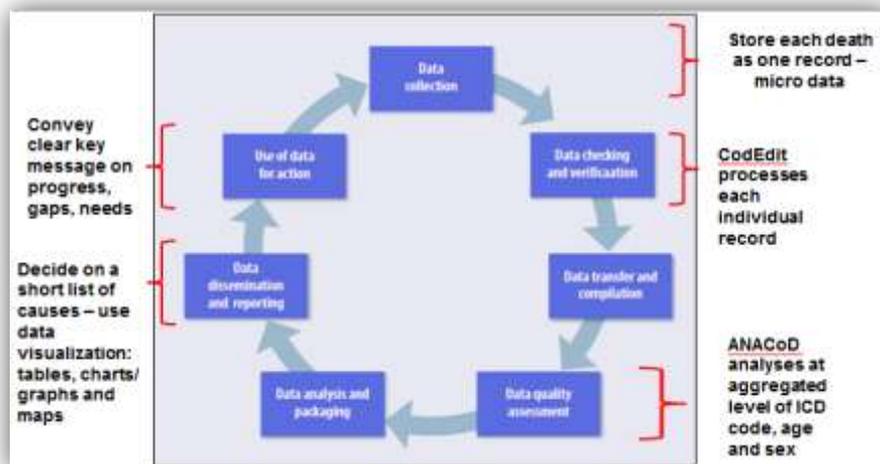
### Completeness

- There is a lack of global or regional guidance on the estimation completeness of civil registration systems. UNECA is currently collaborating with UNESCAP in the development of such guidance.
- Often, published death registration completeness are usually difficult to interpret and to compare, primarily due to varying methods of computation used across countries and also due to the lack of complementary explanations and meta data on the processes used in the estimations.
- Published death registration completeness statistics are difficult to interpret and compare
- Our ability to measure death registration completeness and quality depends on availability of complementary data sources (e.g. Census, Survey, HDSS, SRS, SAVVY)

- Completeness estimation method matters, and context specific approach is needed (based on available data and improvement targets/strategy)
- “One size fits all” approach is neither appropriate nor strategic.
- Analysis of registration completeness should go hand-in-hand with assessment of quality.

### Leading causes of death and data quality

- **Goal 1. Analyse the mortality levels:** Compute total deaths by sex and age from records with or without cause-of-death information. Compare results with other sources of data. If possible, compute life tables.
- **Goal 2: Analyse the causes of death:** Code data to detailed ICD-10 codes whenever possible – (coders); Invest in setting up a solid long-term data base - (IT support); Input each event (death) as a single record with the relevant variables in the data base - (admin and IT support). Compile the data for analyses– (IT and statistical officers); Analyse data (demographers, statisticians); Decide on a short list of causes for releasing results – consider disease priorities, confidentiality issues.
- Quality issues can exist with cause of death data. CoDEdit builds capacity to perform routine checks.
- The importance of metadata in the production mortality and CoD data and statistics in countries should be reiterated.
- Proper archival of data during collection and even after analysis is critical. Data should be stored in a way that ensures that it is useable and understandable to those who need it.
- There is a need to provide countries with comprehensive guidance on how to deal with issues of confidentiality in the release of death and CoD data.
- Having an external back up facility for all statistical data is very critical in minimizing or eliminating risks of data loss.



## Conclusion: Next Steps

There are three key areas to focus on in the near future, building on the deliberations of the workshop. There is an increasing need to develop the required standards, methodologies, and guidelines that would support African countries in improving mortality and CoD collections. The resources to be developed and provided to countries are three-fold:

- **Online and printable resource** designed for country guidance and planning on health facilities collections and ICD; community deaths; administrative data; samples surveys, census; and special or difficult collections (such as emergency settings).
- **Methodology development** based on case studies and country experiences. A small methodology group was formed at the workshop that would be responsible for the development of concepts and methodology guidance.
- **Technical development:** Further development of technical guidance and resources and building of in-depth expertise and capacity.

### Immediate Need: Guidance on Mortality System Design and Development

An immediate need for country support should focus on **development of mortality systems in hospitals, building linkages with civil registration systems, improving data collection for community deaths, analyses, and adaptive approaches on scaling up and changing needs**. There is also a need to review comprehensive assessment tools and processes, develop baseline reporting standards and procedures as well as working with government institutions and other stakeholders to model registration laws including post-conflict mortality assessments.

**A lot of health facility data are collected and procedures for such collection should be reviewed and standardized.** This can be accomplished by developing comprehensive guidelines on implementation of data collection in health facilities, providing ICD training and resources, building CRVS notification and ensuring that these initiatives benefit public and private health facilities.

**Methodological development** is inevitable to ensure that countries have clear guidelines in collection methodology, quality assurance processes, and tools to assess or improve data quality. Methodological development should also draw on other existing in-hospital sources such as mortuary guidelines and maternal death audits.

To improve mortality data collection in communities, **guidelines for data collection on community deaths should be developed**. Efforts should be made to increase awareness of the role of mortality data in planning and find novel ways for communities to report deaths.

### Priority Development Areas

Using adaptive approaches on scaling up and changing needs, it was agreed that there was an immediate need for country support to focus on:

- **Focussing on country plans for better design for mortality statistics as a system**, focussed on improving death registration, hospital mortality data and community deaths data, and incorporating multiple elements in their design. To support these priorities, it was also agreed that:
  - There is a need to **review comprehensive assessment tools and processes**, develop baseline reporting standards and procedures as well as working with government institutions and other stakeholders to model registration laws including post-conflict mortality assessments.

- **Methodological design and development work** should be prioritised to ensure that countries have clear guidelines in collection design, methodology, quality assurance processes, and tools to assess or improve data quality. Methodological development should also draw on other existing in-hospital sources such as mortuary guidelines and maternal death audits.
- **Building linkages with civil registration systems as a priority** through better notification of events, and using administrative and other sources of data including health notifications, burial notifications and other records advising of a death. These systems rely on better guidance on data linkage, including ethics, confidentiality and security guidelines.
- **Immediate development of mortality systems in hospitals, including review and standardization of health facility data collections.** This can be accomplished by developing comprehensive guidelines on implementation of data collection in health facilities, providing ICD training and resources (including simplified approaches), building CRVS notification and ensuring that these initiatives benefit public and private health facilities. Whilst many resources exist, the approach should focus on bringing together sources of a regional and global standard, for best country support.
- **Improving data collection for community deaths, including development of guidelines for data collection on community deaths.** Efforts should be made to increase awareness of the role of mortality data in planning and find novel ways for communities to report deaths. It was agreed that a significant body of work is required here, and should be developed cohesively.
- A critical focus on better guidance on mortality data collections and statistics in situations of **conflict or health emergency**, drawing on interregional experiences with conflict and Ebola.
- **Analysis of data**, including use of quality tools and development of reporting tools.

### **Immediate Development: Case Studies**

Case studies should be developed that include country CRVS and mortality statistics plans. Use available evidence from countries such as Egypt, Kenya, Mozambique, Sierra Leone, Tunisia, and South Africa. The INDEPTH Network experience in mortality data collection in communities will be a milestone in showcasing how mortality data systems work.

### **Methodology Working Group**

A lot of issues were discussed that need a small methodology group to focus on developing concepts and guidelines to improve mortality data collection and analysis in Africa. This group will work in consultation with relevant experts. The **methodology should focus on operations that are grounded in country experiences.**

## Annex 1: Concept Note – African Mortality Statistics Expert Workshop

WHO EMRO, Cairo

28 September – 1 October 2015

### Background

In February 2015, the African Ministers responsible for Civil Registration, including many African Ministers of Health, made a declaration ('Yamoussoukro Declaration'<sup>1</sup>) recognising the critical need for real time mortality data in African countries, especially in the aftermath of the Ebola outbreak. The declaration specifically called on WHO in conjunction with its Pan African partners to intensify this effort in developing mortality data at country level (box below). Health Ministers in Africa, including those in the WHO EMRO region, have also specifically committed to improvement of CRVS systems, and mortality data, as a priority<sup>2</sup>.

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*'...Recognizing that the Ebola epidemic has shown that the need for death registration and real time cause-of-death information is no longer optional but critical;*

*....Realising the centrality of civil registration based vital statistics in providing data to inform health, economic and social policies, for good governance and accountability, and in advancing the data revolution;*

*....Appreciating the increased and continuing involvement of the African Ministers of Health in improving registration of births and deaths, including the collection of information on cause-of-death;*

*....Underscoring the important role of the health sector in the delivery of civil registration services to ensure a coordinated and integrated approach in addressing the challenges of improving CRVS systems in Africa;*

*.... Appreciating the increased and continuing involvement of the African Ministers of Health in improving registration of births and deaths, including the collection of information on cause-of-death;*

*....Call upon WHO, in collaboration with Pan African Organizations and other partners, to intensify their efforts in developing real time death registration and causes of death information systems at country level'*

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Partners agreed at a meeting of the APAI-CRVS Core Group in Zimbabwe June 2015, to develop a regional technical strategy for improving mortality data in Africa; recognising the expertise that already exists on the Continent in many areas of mortality collection – from surveillance to sample systems, surveys, Census and hospital collections –which is now supported by an African partnership focussed on improving mortality data through the APAI-CRVS programme.

A regional reference group<sup>3</sup> was formed in August 2015 to consider how best to progress mortality statistics as an agenda within the APAI-CRVS programme in Africa.

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<sup>1</sup>UNECA 2015. The Third Conference of African Ministers Responsible for Civil Registration: Yamoussoukro Declaration. [http://unstats.un.org/UNSD/demographic/CRVS/Global\\_CRVS\\_Docs/news/ThirdConf\\_resolutions.pdf](http://unstats.un.org/UNSD/demographic/CRVS/Global_CRVS_Docs/news/ThirdConf_resolutions.pdf)

<sup>2</sup>WHO EMRO 2013. Regional committee resolution: Regional strategy for the improvement of civil registration and vital statistics systems 2014–2019. <http://www.emro.who.int/entity/civil-registration-statistics/index.html>

<sup>3</sup>Led by ASSD, WHO and UNECA, and comprising representatives from African Union, Africa Development Bank, UNFPA, World Bank, Global Fund, INDEPTH network, Bloomberg Philanthropies.

The group identified that the challenges are many; including multiple fragmented and uncoordinated systems, the incorrect perception of a lack of regional expertise, and a lack of regional institutions to provide support.

- However the group also agreed that there are also opportunities: countries have committed politically and technically to improving their mortality statistics. There is new thinking in this area – methodological, analytical, and developmental – which is exciting. Most importantly, Africa houses significant and varied technical expertise, along with extensive practical implementation experiences. It hosts a strong technical institutions and partnerships, backed politically, through the APAI-CRVS programme.

The consequent strategy is the result of collaboration between WHO, UNECA, ASSD, and their many regional and global partners committed to ensuring that for the future, Africa has a better ability to generate and use its own mortality and CRVS data for its own health, social and economic policy needs.

**The strategy has the highest possible political commitments:** based on the call of African Ministers and country demand and commitments, the strategy for improving mortality statistics is embedded within the APAI-CRVS five year strategy, and so included in the SHASA statistical development programme for Africa, to be presented at the UN General Assembly in September 2015.

#### Concept and Purpose

The regional reference group agreed that a meeting of experts be held, at WHO EMRO's invitation, the meeting will be held in Cairo from 28 September to 2 October (with a possible fifth day on October 2 for country visits to registries, health facilities and community data collections).

The purpose of the meeting is to gather African experts in mortality statistics collections together to:

- **collaborate on new technical guidance** to be provided to countries for designing better mortality statistics systems; and
- **develop a pool of available experts** to deploy to countries to support technical improvement and results in mortality data collections, especially for death registration, hospital deaths and integrating systems for community deaths.

#### Outcome

The outcome of the meeting will be:

- new technical guidance prepared by WHO, UNECA and ASSD for use in African and Middle-Eastern countries to improve mortality statistics; and
- a pool of experts available to provide advice on strengthening and improving multiple statistical systems in countries.

## Annex 2: Workshop Programme

WHO EMRO, Cairo, Egypt: 28 September – 1 October 2015

*Day one: Monday, 28 September 2015*

### Morning: Designing Better Mortality Data Systems

|               |   |
|---------------|---|
| 08:30 – 09:00 | Registration  |
| 09:00 – 09:15 | <ul style="list-style-type: none"> <li>Welcome and introduction<br/><i>Dr Jaouad Mahjour, DPM</i></li> </ul>  |
| 09:15 – 10:15 | <p>Current Status</p> <ul style="list-style-type: none"> <li>African Context</li> <li>EMRO context</li> <li>Lessons learned from CRVS assessments for improving mortality statistics<br/><i>Dr Arash Rashidian, Dr Raj Mitra, Dr Yacob Zewoldi</i></li> </ul> |
| 10:15 – 10:30 | <i>Coffee break</i>   |
| 10:30 – 11:00 | <ul style="list-style-type: none"> <li>Improving Mortality Statistics in Africa – Technical Strategy 2015 – 2020<br/><i>Dr Raj Mitra</i></li> </ul>   |
| 11:00 – 12:00 | <ul style="list-style-type: none"> <li>Discussion – country experiences and Technical Strategy<br/><i>Dr Mohamed Ali</i></li> </ul>   |
| 12:00 – 13:00 | <i>Break</i>  |

### Afternoon: Mapping Mortality Data Sources and Needs

|               |  |
|---------------|--|
| 13:00 – 14:00 | <p>Emerging Need: Designing mortality systems</p> <ul style="list-style-type: none"> <li>WHO advisory (November paper)</li> <li>Resources and Handbook Concept</li> <li>From death to burial – mapping key data sources</li> <li>Multiple country collections – opportunities for baseline reporting<br/><i>Dr Raj Mitra (session chair), Mrs Anneke Schmider</i></li> </ul> |
| 14:00 – 15:00 | <p>Mapping and integrating data sources</p> <ul style="list-style-type: none"> <li>The Challenge of Multiple Community Collections</li> <li>Integrating sources in the Kenya<br/><i>Mozambique Rep &amp; Kenya Rep</i></li> </ul>  |
| 15:00 – 15:15 | <i>Coffee break</i>  |
| 15:15 – 16:30 | <p>Discussion: designing country mortality statistics systems</p> <ul style="list-style-type: none"> <li>What information will countries need?<br/><i>Dr Raj Mitra</i></li> </ul>  |

*Day Two: Tuesday, 29 September 2015*

**Morning: Evolution in Community Mortality Collections**

|  |   |
|--|---|
| 09:00 – 09:45  | <p>Introduction:</p> <ul style="list-style-type: none"><li>• Evolution of community mortality data collection approaches</li><li>• New thinking about integrating mortality data and linking to CRVS systems: surveillance, SAVVY</li></ul> <p><i>Dr Carla Abouzahr (session chair)</i></p>   |
| 09:45 – 10:30<br>(Webex)                                   | <p><b>Verbal Autopsy</b> – instruments, automated approaches, scaling, criteria for routine use</p> <p><i>Dr Mohamed Ali, Dr Robert Jakob</i></p>   |
| 10:30 – 10:45  | <p><i>Coffee break</i></p>  |
| 10:45 – 11:15  | <p><b>Moving Surveillance Forward with CRVS: the INDEPTH view</b></p>   |
| 10:15 –12:00   | <p>Discussion</p> <ul style="list-style-type: none"><li>• Mapping: including cultural practices and entry points</li><li>• Building representativeness and coverage: Sampling and methodology</li></ul> <p><i>Dr Carla Abouzahr</i></p> <p>Death registration in Egypt</p> <p><i>Dr Amany Gayed</i></p>   |
| 12:00 –13:00   | <p><i>Break</i></p>   |
| <p><b>Afternoon: The Challenge of scale and design</b></p> |   |
| 13:00 –13:30   | <p><b>The challenge of scaling up:</b></p> <ul style="list-style-type: none"><li>• Mapping country contexts and best entry points (administrative data)</li><li>• From research to innovation to scaled production</li></ul> <p><i>Mrs Anneke Schmider(session chair)</i></p> <ul style="list-style-type: none"><li>• Potential of IT - APAI CRVS Digitization Guidelines</li></ul> <p><i>Jembe</i></p> |
| 13:30 –15:00   | <p><b>Country Examples</b></p> <ul style="list-style-type: none"><li>• Tanzania: HDSS, SAVVY and technology - <i>INDEPTH</i></li><li>• Kenya: HDSS sites- <i>INDEPTH</i></li><li>• Zambia – SRS and CRVS- <i>CDC</i></li><li>• Mozambique planning- <i>Mozambique Representative</i></li></ul>  |
| 15:00 –15:15   | <p><i>Coffee break</i></p>  |
| 15:15 – 16:30  | <p><b>Discussion:</b></p> <ul style="list-style-type: none"><li>• Better Guidance for scale and design</li><li>• Community mortality collections – Overall approach to support assessments and methodology gaps</li><li>• ICT design and planning</li></ul> <p><i>Dr Mohamed Ali</i></p>  |

*Day Three: Wednesday, 30 September 2015*

**Morning: Designing Better Mortality Collections in Hospitals**

|                          |  |
|--------------------------|--|
| 08:30 – 09:00            | CRVS Planning in Mozambique (Mozambique)   |
| 09:00 – 10:00            | <b>Designing Better Hospital Collections</b> <ul style="list-style-type: none"><li>• Targets for hospital systems</li><li>• Mapping Hospital deaths</li><li>• Death Notification: Linkages to CRVS</li></ul> <i>Dr Carla Abouzahr (session chair)</i>  |
| 10:00 – 10:30<br>(Webex) | <b>The International Classification of Disease</b> <ul style="list-style-type: none"><li>• Medical certification, cause of death coding</li><li>• Interim Steps: Use of the Simplified List, DHIS</li></ul> <i>Dr Robert Jakob, Dr Yusuf Hemed</i>   |
| 10:30 – 10:45            | <i>Coffee break</i>  |
| <b>10:45 – 11:30</b>     | <b>Country Experiences</b> <ul style="list-style-type: none"><li>• Coding automation in practice: The Case of South Africa – <i>South Africa</i></li><li>• Improving mortality data in Tunisia - <i>Tunisia</i></li><li>• Improving Hospital Systems in Mozambique - <i>Mozambique</i></li></ul> |
| 11:30 – 12:00            | <b>Discussions</b> <ul style="list-style-type: none"><li>• Hospital collections and health facilities</li><li>• Practical support</li></ul> <i>Dr Carla Abouzahr, Dr Hongyi Xu</i>   |
| 12:00 – 13:00            | <i>Break</i>   |

**Afternoon: The Role of Surveys and Census**

|               |   |
|---------------|---|
| 13:00 – 14:00 | <b>Surveys and Census</b> <ul style="list-style-type: none"><li>• Role and evolution</li><li>• Challenges and strengths</li><li>• Examples</li><li>• Current distribution in Africa (from WB paper)</li><li>• Future needs and vision</li></ul> <i>Dr Mohamed Ali (session chair), Dr Raj Mitra</i> |
| 14:00 – 15:00 | <b>Emergency collections</b> <ul style="list-style-type: none"><li>• Collection of data in conflict and post-conflict settings</li><li>• Emergency collections: example of Ebola</li></ul> <i>Dr Romesh Silva, Dr Hongyi Xu</i>   |
| 15:00 – 15:15 | <i>Coffee break</i>   |
| 15:15 – 15:45 | <b>Technologies for Mortality Collection (Anneke Schmider)</b> <ul style="list-style-type: none"><li>• Potential of IT – APAI CRS Digitization guidelines (<i>Jembe</i>)</li></ul>  |
| 15:45 – 16:30 | <b>Discussion:</b> <ul style="list-style-type: none"><li>• Role surveys, census and emergency collection in designing country mortality statistics systems <i>Dr Mohamed Ali</i></li></ul>  |

*Day Four: Thursday, 1 October 2015*

**Morning: Data Analysis**

|               |  |
|---------------|--|
| 08:30 – 09:00 | <b>Bringing it all together</b> <ul style="list-style-type: none"><li>• Data reconciliation</li></ul> <i>Dr Carla Abouzahr (session chair), Dr Hongyi Xu</i>   |
| 09:00 – 09:45 | <b>Using the data: concepts, challenges, quality</b> <ul style="list-style-type: none"><li>• Interim reporting</li><li>• Measuring completeness and coverage</li><li>• Demographic analysis (all cause)</li><li>• Leading causes of death</li></ul> <i>Dr Carla Abouzahr, Dr Romesh Silva</i>  |
| 09:45 – 10:15 | <b>Data Quality and Analysis</b> ( <i>Dr Doris MaFat</i> )   |
| 10:15– 10:30  | <i>Coffee break</i>  |
| 10:30 – 11:00 | <b>Data Sharing: Confidentiality, ethics, agreements for use</b> <ul style="list-style-type: none"><li>• Data linkage and sharing - Ethics, security, protocols and guidance</li><li>• Using new technologies</li><li>• Example of the NCIS</li></ul> <i>Mrs Anneke Schmider</i><br><b>Data Sharing and Security in South Africa</b> |
| 11:00 –11:30  | <b>Comprehensive Assessments and Coordinating Partners in Country</b> <ul style="list-style-type: none"><li>• Review of comprehensive assessment and development of investment plans</li><li>• Coordination in the context of CRVS</li><li>• The Role for Mortality Technical Working Groups</li></ul> <i>Raj Mitra</i>              |
| 11:30 – 12:30 | <b>Next Steps</b> <ul style="list-style-type: none"><li>• Operational Guidance – notes from discussions and next steps (<i>Anneke Schmider</i>)</li><li>• Methods – notes from discussions and next steps (<i>Carla Abouzahr</i>)</li><li>• APAI-CRVS program and expertise (<i>Raj Mitra</i>)</li></ul>                             |
| 12:00 –12:45  | <i>Finish</i>  |

## **Annex 3: List of Participants**

Note: \* Did not attend the meeting.

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