



Better Data for Women and Children: Strengthening Civil Registration and Vital Statistics Across the Continuum of Care

Technical Meeting Report

4th-6th October, 2016
New York, USA



Acknowledgements

This report was written by Kristen Wenz for the United Nations Children's Fund (UNICEF) with the support of Carla Abouzahr on behalf of the World Health Organization (WHO). UNICEF appreciates the support of Gavi, the Vaccine Alliance (Gavi) for their generous sponsorship of the meeting, and also the Centers for Disease Control and Prevention (CDC), the World Bank Group and WHO for co-hosting the event.

This report has benefited from the valuable inputs of many colleagues.

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The meeting sponsor:

Gavi, the Vaccine Alliance

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March, 2017

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Acronyms

AIDS	Acquired Immunodeficiency Syndrome
BPM	Business process mapping
CDC	Centers for Disease Control and Prevention
COC	Continuum of care
CHW	Community health worker
CRVS	Civil registration and vital statistics
DHIS2	District Health Information Software 2
DPT1	Diphtheria, Pertussis and Typhoid, 1 st vaccination
EA	Enterprise architecture
ECA	Economic Commission for Africa
EIR	Electronic Immunization Registry
ESCAP	Economic and Social Commission for Asia and the Pacific
Gavi	Gavi, the Vaccine Alliance
HDC	Health Data Collaborative
HDSS	Health and Demographic Surveillance System
HIS	Health Information System
HMIS	Health management information system
ICD	International Statistical Classification of Diseases and Related Health Problems
ICT	Information and communications technology
ID	Identification
OLMIS	Orphans and Vulnerable Children Longitudinal Management Information System
MCCD	Medical Certificate of Cause of Death
MNCH	Material, newborn and child health
MDG	Millennium Development Goals
MDSR	Maternal Death Surveillance and Response
NCD	Noncommunicable diseases
NGO	Nongovernmental organization
OpenHIE	Open Health Information Exchange
OVC	Orphans and vulnerable children
PEPFAR	United States President's Emergency Plan for AIDS Relief
RMNCAH	Reproductive, maternal, newborn, child and adolescent health
SDGs	Sustainable Development Goals
SMoL	Start-up Mortality List
UHC	Universal health coverage
UNHCR	Office of the United Nations High Commissioner for Refugees
UNICEF	United Nations Children's Fund
UNSD	United Nations Statistics Division
USAID	United States Agency for International Development
WB	World Bank Group
WHO	World Health Organization
WHO-FIC	World Health Organization Family of International Classifications

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Executive summary

The technical meeting, *Better Data for Women and Children: Strengthening CRVS Across the Continuum of Care* took place at UNICEF HQ in New York from 4 - 6 October, 2016. The meeting brought together country program experts, development partners and technical experts across health and other sectors, including immunization, maternal, newborn and child health, health data systems, civil registry and vital statistics and child protection. The meeting was sponsored by Gavi and coordinated by UNICEF, WHO, CDC and World Bank Group.

The purpose of the meeting was to understand and identify practical ways of strengthening collaboration and linkages between reproductive maternal, newborn, child and adolescent health (RMNCAH) services and civil registration and vital statistics (CRVS) systems to ensure that all births and deaths recorded by programs for women's and children's health are notified, registered and certified by civil registration authorities.

The meeting was designed to share and discuss:

- Knowledge and experiences in RMNCAH-CRVS innovations;
- Coordination between health systems and programs and CRVS stakeholders;
- Promising RMNCAH-CRVS innovations for testing by country and regional stakeholders;
- Development of guidance for country stakeholders and development partners.

Health workers, by virtue of their extended reach to individuals, families and communities, can play important roles in notifying civil registrars of the occurrence of births and deaths and characteristics associated with those events. They can also work with families to ensure that births and deaths are subsequently registered with authorities to ensure that the family receives birth/death certificates. Health programs benefit from fully functioning CRVS by way of improved real time data on births and deaths at local and national levels, and enabling more reliable aggregate data for both numerators and denominators for the calculation of major RMNCAH indicators as well as better general health policy and planning.

Building on the December 2013 technical meeting; *Strengthening CRVS Systems Through Innovative Approaches in the Health Sector*¹ participants reviewed evidence and country experiences from recent efforts to leverage the health sector to improve the recording, notification, registration, and certification of births and deaths and causes of death.

Key RMNCAH and CRVS themes explored included:

- Strengthening CRVS through the RMNCAH Continuum of Care
- The current status of CRVS and health system interoperability
- Strengthening linkages between immunization and CRVS
- Pregnancy tracking and other RMNCAH opportunities for CRVS
- Strengthening CRVS through health facility data
- Challenges and opportunities of CRVS implementation in hard to reach populations

Meeting participants agreed that RMNCAH programs face similar challenges in terms of data availability and quality and estimating denominators for reliable calculation of rates and ratios and for reporting for key initiatives such as Every Woman, Every Child. At the same time, CRVS systems are being challenged to deliver the administrative and legal benefits of civil registration as well as to improve the availability and quality of vital statistics for progress monitoring, including of the SDGs. Participants discussed innovations to help forge links across the continuum of care and CRVS, and identified priority areas for collaboration between the health sector and CRVS that could be mutually beneficial, summarized below.

Joint assessments and business process mapping should be prioritized: Collaboration between RMNCAH, health information and CRVS stakeholders in assessments of CRVS systems would help identify bottlenecks, overlap, and areas where standard procedures are not being followed. The involvement of RMNCAH programs, which are often responsible to record births, deaths and causes of death, in CRVS business process mapping would help foster a shared understanding of how to operationalize links between CRVS systems and the RMNCAH continuum of care.

Joint development of Information, Communications and Technology (ICT) should be pursued: ICT has the potential to provide transformative improvements in both RMNCAH and CRVS systems by streamlining and extending registration coverage, integrating data from multiple systems, securely storing data at scale, all in a cost-effective way. The joint development of RMNCAH/CRVS shared data architecture is a prerequisite for IT introduction and interoperability between health, CRVS and related systems such as unique individual identifiers (IDs) (P25).

Data collection forms and methods should be redesigned: Some data collection instruments may need to be engineered to incorporate individual data collected for interventions across the continuum of care, and permit aggregations and analyses across geographies and over time. This necessitates the development of common data standards across RMNCAH programs. Information collected in the course of RMNCAH program implementation should be made available in the level of detail and with the content required for the registration and certification and births and deaths, including causes of death, as well as for program monitoring purposes.

Data management and sharing protocols should be developed for information sharing: The concept of interoperability implies the development of protocols for sharing information and data across and between health programs and CRVS systems and related sectors (e.g. ID systems and population registers). For this to happen it is imperative to work with communities to address issues of confidentiality, privacy and data security within a sound legal and governance framework.

Joint capacities need to be developed: There is an urgent need to develop the capacities and human resources needed to implement the innovations now becoming available. Training materials that can be adapted to diverse settings are needed alongside institutional mechanisms for capacity development, with a particular focus on RMNCAH and CRVS interoperability. Various cadres (i.e. social workers, case managers, midwives, and community health workers) need to be mandated and trained to increase education around notifications of births and deaths and ensure that they are officially registered according to international standards.

Improvement in implementation research: A stronger research effort is needed to support evidence-based policy and practice for CRVS in countries and how this could be linked to interventions across the RMNCAH continuum of care. Consensus needs to be built around a shared CRVS-RMNCAH research agenda that recognizes the contribution of different players and the mutual benefits that each would derive from closer collaboration. As part of this, it is essential to bring together lessons learned from country experiences, such as how to facilitate registration among marginalized and vulnerable populations, and ways of scaling up projects designed to introduce ICT and enhance interoperability.

A summary of the challenges and prioritized recommendations to address these challenges are included in this report. Recommendations are directed to CRVS stakeholders, to RMNCAH programs across the continuum of care and to donors and development partners.

Background

Women's and children's health: An accountability imperative

Building on the success of the Millennium Development Goals, which provided the development framework from 2000-2015 for developing countries, the 17 Sustainable Development Goals (SDGs) of the 2030 Agenda for Sustainable Development² were adopted by world leaders in September 2015 and define the development agenda from 2016 to 2030 for all countries. The *Global Strategy for Women's, Children's and Adolescents' Health (2016-2030)*³ is a roadmap to take forward the SDGs which strive to achieve the highest attainable standard of health for all women, children and adolescents. It is associated with a monitoring and accountability process described in the report, *Country data, universal accountability: Monitoring priorities for the Global Strategy for Women's, Children's and Adolescents' Health (2016-2030)*.⁴ As part of the overall strategy, and in alignment with the SDGs, the aim is to strengthen country data including CRVS systems. The Global Strategy has 60 key indicators against which progress will be monitored, including the proportion of children whose births have been registered with a civil authority by age; and the proportion of countries that have achieved 100% birth registration and 80% death registration.⁵ The *Every Newborn: An action plan to end preventable deaths (ENAP)* adopted in 2014 sets out a clear vision of how to improve newborn health and prevent fetal deaths, and includes a specific objective by 2020 to 'count every birth and death for women and babies including stillbirths, invest in CRVS, and innovate to improve and ensure the poorest are counted.'⁶ The plan calls for governments and partners to invest in improving birth and death registration systems and consider innovative mechanisms for gathering data. In addition, specific RMNCAH programs along the continuum of care, such as immunization, need accurate local and national denominators to measure coverage and assess equity. For example, the Gavi mission indicators include: under five mortality, future deaths averted and children fully immunized (<http://www.gavi.org/results/goal-level-indicators/>).

Effective monitoring of progress on women's, children's and adolescents' health relies on well-functioning country health information systems that draw data from multiple sources such as civil registration and vital statistics (CRVS) systems, health facilities, administrative data sources, surveillance systems and household surveys. CRVS is the preferred source of data to track seven of the 16 key indicators (Box 1). However, the Country Data, Universal Accountability report found that health information systems in many countries are weak and not able to systematically collect the required health data, and that in many low and middle-income countries, CRVS and health information systems need substantial strengthening, with much greater emphasis on supportive legal and policy frameworks, domestic administrative organization, statistical and analytic capability, and use of data for policy and programs.

Box 1. RMNCAH monitoring indicators for which CRVS is the preferred data source

- **Maternal mortality ratio**
- **Under 5 mortality rate**
- **Neonatal mortality rate**
- **Stillbirth rate**
- **Adolescent mortality rate**
- **Adolescent birth rate**
- **Proportion of children under 5 years of age whose births have been registered with a civil authority**

In response to the urgent need for better data to respond to the monitoring and accountability challenges of the Sustainable Development Goals (SDGs), the Health Data Collaborative (HDC) was established in 2016.⁷ This is a joint effort by countries, development partners, civil society and academia to strengthen country health information systems, improve the quality of health data and track progress towards the SDGs. Building on a series of CRVS initiatives and activities at global and regional levels,^{8 9 10 11 12 13 14} the HDC launched a package of tools and guidance to support strengthening of country health data and CRVS systems, with enhanced coordination of global health data initiatives and is establishing partnerships with low and middle-income countries to develop common investment plans to strengthen health data systems and CRVS. Building on existing CRVS momentum in the health sector in 2016, HDC partners including the World Bank Group are developing CRVS training packages to be delivered through E-learning techniques, and working to align partners for harmonized country support and implementation of best practices. Health partners continue to work together to seek to strengthen hospital and other data to improve health data and CRVS.

The benefits of birth and death registration

States have the primary responsibility for civil registration. The CRVS system serves as an important instrument through which fundamental human rights are in line with several international declarations and conventions. Civil registration is defined as the continuous, permanent, compulsory and universal recording of the occurrence and characteristics of vital events, notably births and deaths but also marriages, adoptions and divorces as provided through decree or regulation in accordance with the legal requirements in each country.¹⁵ The lack of registration and subsequent documentation increases the risk of several rights violations, lack of protection, statelessness, child marriage and exploitation.¹⁶

The birth certificate is a 'breeder document' that helps establish a legal identity and nationality by serving as an official record of key information such as the name of the child, date and place of birth and the name of child's parents. Birth certificates facilitate access to a range of rights such as economic and social services, including health care, education, social protection, financial inclusion, access to juvenile justice, formal employment and participation in elections.¹⁷ For refugees and other displaced populations, registration can enable durable solutions or repatriation of displaced populations by documenting legal ties that underpin nationality claims which prevent statelessness.¹⁸ In emergencies, the possession of a birth certificate can help in repatriation or reunification of minors separated from their families in times of conflict or disaster.^{19 20 21} The registration of deaths and provision of death certificates enables family members to make claims of inheritance, property, land, insurance, and survivor and spousal benefits. It enables the surviving men, women and children to be acknowledged and accorded protection and exercise their rights.

Alongside these protection, legal and administrative benefits, a fully functioning CRVS system generates information that offers the most effective and efficient foundation for a country's vital statistics system. The civil registration system can provide a continuous real-time flow of statistics from the smallest administrative divisions, a characteristic that no other data collection system can furnish. Knowing the size and characteristics of a country's population in a timely manner is a prerequisite to socioeconomic planning and informed decision-making. Information about numbers of births and deaths is essential for generating reliable statistics on population size, trends in fertility and mortality, and on patterns and causes of death. These data enable governments to monitor key demographic and health indicators, including infant, child and maternal mortality, and target resources and interventions by geography and population group. In countries where civil registration has a high level of coverage, it is the preferred source of population data. By contrast, partial or inaccurate registration of births and deaths results in incomplete and unreliable data of limited value for evidence based decision-making.

Current status of birth and death registration

National CRVS systems vary considerably in terms of coverage and accuracy of the information collected.²² Currently, birth registration is particularly weak in most African countries and in large parts of Asia (Figure 1). The situation regarding death registration is considerably worse (Figure 2 and P3) and very few countries in Africa and Asia are able to produce usable cause of death statistics.²³

Figure 1. Birth registration coverage

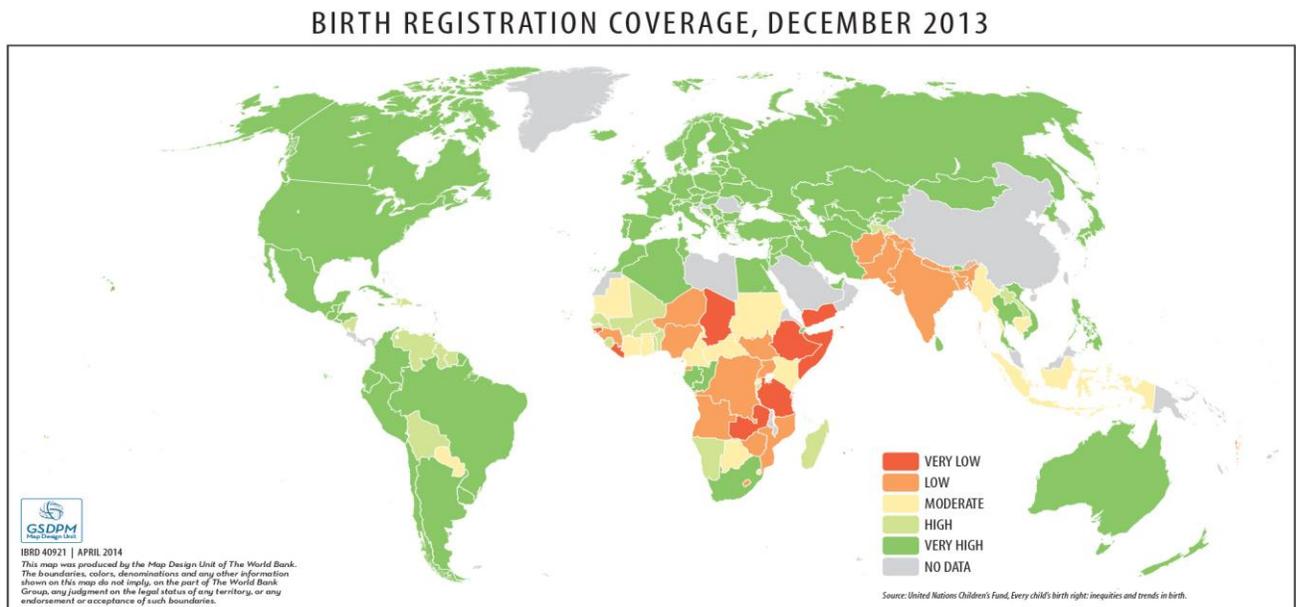
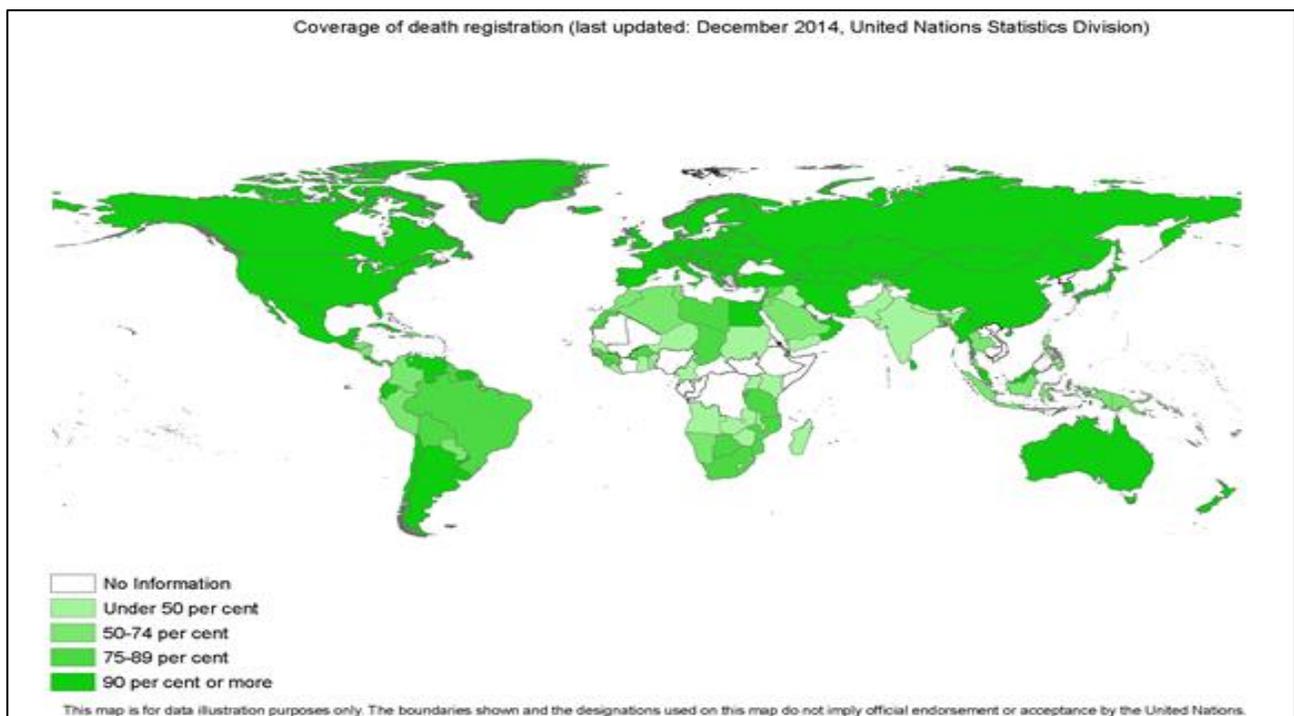


Figure 2. Death registration coverage according to UN estimates (updated 2014)²⁴



Global momentum for CRVS: The Sustainable Development Goals

Building on the success of the Millennium Development Goals, which provided the development framework from 2000-2015 for developing countries, the 17 Sustainable Development Goals (SDGs) of the 2030 Agenda for Sustainable Development²⁵ were adopted by world leaders in September 2015 and define the development agenda from 2016 to 2030 for all countries. CRVS underpins many of the SDGs and is a target in its own right under Goals 16 and 17 as the foundational system for the establishment of legal identity. CRVS systems contribute to the achievement of goals such as access to education, social inclusion, and prevention of violence and exploitation.

Furthermore, CRVS systems are necessary for monitoring key outcome indicators such as reductions in maternal and child mortality and non-communicable disease (NCD) related deaths, and the elimination of inequalities (especially gender inequalities). Targets for Universal Health Coverage (UHC) and health systems strengthening will also arguably rely on improved population data such as delivered through CRVS systems.²⁶ A functioning CRVS system provides important information about the whole population, which is a key SDG concept linked to the vision of 'leaving no-one behind'. Table 1 summarizes the multifaceted contributions of CRVS systems in achieving SDG targets as well as in monitoring progress towards them.

Table 1. Contributions of CRVS systems in achieving SDG targets & monitoring progress

	Goal/target	Contribution of CRVS	Data derived from CRVS
1	End Poverty in all forms everywhere		
1.3	Implement social welfare and protection systems with substantial coverage of the poor and the vulnerable.	CRVS provides documentation to support legal identity	Birth registration completeness and key disaggregation
1.4	Ensure that all men and women have equal rights to resources and access to services		
1.5	Build the resilience of the poor and those in vulnerable situations		
2	Zero hunger		
2.1	End hunger and ensure access to food, especially vulnerable people, infants and children	Information on births: and deaths associated with malnutrition	Total births Deaths due to malnutrition by age/sex
2.2	End all forms of malnutrition in children adolescents, pregnant and lactating women, older people		
3	Ensure healthy lives and promote wellbeing for all ages		
3.1	Reduce maternal mortality	Measurement of the indicator	Total births Maternal deaths
3.2	End preventable neonatal, infant and child mortality		Total births Under 5 deaths by age, sex and cause of death
3.3	End the epidemic of AIDS, TB, malaria and other communicable diseases		Deaths by age, sex and cause of death

3.4	Reduce premature mortality from NCDs		
3.5	Halve deaths from road traffic accidents		
4	Ensure inclusive and equitable quality education		
4.1 4.2 4.3	Ensure access to education for all	Access to education requires birth certificate	Birth registration coverage by age 5 by geography and sex
4.5	End gender disparities in education		
5	Achieve gender equality and empower all women and girls		
5.1	End discrimination against women	Birth registration central to social inclusion	Birth registration completeness by sex
5.2	Eliminate violence against women and girls	Women and girls with legal identity are better protected against trafficking and child marriage	
5.3	Eliminate harmful practices		Age at marriage by sex
10	Reduce inequality within and among countries		
10.3	Reduce inequalities of outcome, including by eliminating discriminatory laws, policies and practices	Information about disparities- both within populations and sub-nationally- is critical to inform policies and address inequalities	CRVS registration completeness nationally and sub-nationally
10.4	Adopt policies, and achieve greater equality		Disaggregated data by sex and age
10.7	Facilitate safe and responsible migration	Identity documentation provided by strong CRVS systems	Birth and death registration completeness
			Procedures for verifying identity documents
16	Peace, justice, inclusive societies and strong institutions		
16.1	Reduce all forms of violence	Direct measurement of the indicator	Cause-specific mortality rates by age and sex
16.2	End abuse, exploitation, trafficking and torture of children	Children with birth certification and legal identity better protected from exploitation	Birth registration coverage by 12 months by sex
16.9	Provide legal identity for all, including birth registration	Direct measurement of the indicator	Birth registration coverage by age and sex
17	Strengthen the means of implementation and partnership for the SDGs		
17.18	Enhance capacity building support and increase the availability of high-quality, timely and reliable data disaggregated by income, gender, age, race, ethnicity, migratory status, disability, geographic location	CRVS is an essential component of a country legal, administrative and statistical system.	Birth registration coverage
			Death registration coverage
			Availability and quality of vital statistics on births and deaths

Meeting overview

The technical meeting *Better Data for Women and Children: Strengthening CRVS Across the Continuum of Care*, took place UNICEF Headquarters (HQ) in New York from 4 - 6 October 2016. The meeting was sponsored by Gavi and coordinated by UNICEF, WHO, CDC and the World Bank Group. The meeting brought together country program experts, development partners and technical experts across health programs and other sectors, including: immunization, maternal, newborn and child health care, health data systems, CRVS, and child protection (see list of participants Annex I).

The purpose of the meeting was to bring together program and development partners to identify ways of strengthening collaboration and linkages between reproductive, maternal, newborn, child and adolescent health (RMNCAH) services and CRVS systems in order to ensure that all births and deaths of which the health sector is aware are notified to civil registration authorities and officially registered. Building on the December, 2013 technical meeting, *Strengthening CRVS Systems Through Innovative Approaches in the Health Sector* which was held in Geneva,²⁷ participants reviewed evidence and country and partner experiences and lessons learnt from recent efforts to leverage the health sector to improve the recording of births and deaths and ensure information from the health sector was sent to the civil registry.

Discussions over the three days were focused around five thematic areas and on potential next steps in furtherance of the aims of the meeting. In introducing each thematic area, there were country, partner and funder presentations describing the scope of the particular topic, country experiences in the area, and the contribution of partners, whether in the form of technical support, research or standard setting. The presentations can be accessed at: <http://bit.ly/2gWuaRt>.

The five thematic areas comprised:

1. Current status of CRVS and health systems interoperability;
2. Data from infancy and childhood: Strengthening linkages between Immunization and CRVS systems;
3. Pregnancy tracking and other RMNCAH opportunities for CRVS;
4. Strengthening CRVS through health facility data;
5. Reaching hard to reach and vulnerable populations.

Anticipated outputs of the meeting included a technical framework development for linking the systems and the development of a program of work. Working group discussions focused on key next steps within each theme and proposed deliverables needed to move forward on each thematic area, namely:

- Common problem statement;
- High priority activities for implementation;
- Proposals for implementation research;
- Plan for guidance documents for countries and partners;
- Suggestions for raising interest and awareness;
- Reaching hard-to-reach and vulnerable population; and
- Funding needs and source.

Summary of presentations

Day 1: Setting the stage: Strengthening CRVS across the continuum of care

P1. What is the continuum of care & how will it strengthen CRVS? (Anneke Schmider, WHO)

- The Global Strategy for Women's, Children's and Adolescents' Health (2016-2030) identified the need to strengthen the availability, accessibility and use of disaggregated data in order to improve understanding of where and how health inequities occur and who is affected.
- Preferred data sources include CRVS systems, facility data, health accounts, surveys and censuses.
- To underpin program planning, monitoring, and financing data collection and management should be complete at the individual level, longitudinal over time and across the continuum of care, standards-based and interoperable with appropriate data linkage and sharing protocols in place.

P2. Overview of latest birth registration data (Claudia Cappa, UNICEF)

- While there has been an overall rise in birth registration levels over the last 15 years, not all regions have made significant progress.
- It is imperative to improve understanding of available CVRS data and systems, specifically opportunities and investments needed. In addition, there is a need to develop and test new questions for use in household surveys, such as timing of registration, barriers, costs etc.

P3. CRVS goals and targets (Sam Mills, World Bank)

- The Global CRVS Scaling Up Investment Plan (2015-2024), developed on the basis of the Consultative Stakeholder Workshop on CRVS, in Addis Ababa, Ethiopia April 28-29, 2014 and launched at the Maternal, Newborn and Child Health Summit, in Toronto, Canada May 28-30, 2014 hosted by the Prime Minister of Canada to set out goals and targets to be achieved by 2030.
- The SDGs have also integrated CRVS goals, including SDG 16.9 (by 2030 provide legal identity for all, including birth registration) and 17.19 (proportion of countries that have achieved 100% birth registration and 80% death registration by 2030).
- Currently, birth registration lags behind key interventions for women's and children's health, including coverage of antenatal care (1+ visits) and DPT1 immunization. There are many opportunities to increase birth and death registration completeness, for example during antenatal care and immunization visits and maternal care tracking systems, by ensuring that all births and deaths that occur in health facilities are registered, and community health outreach. Programs for maternal death surveillance and response offer important entry points for improved identification and registration of maternal and perinatal deaths.
- There are mutual benefits for both CRVS and RMNCAH programs through better collaboration. Improved CRVS systems will reduce the need for statistical modeled estimates for monitoring maternal and child mortality, generate sub-national level (district) estimates of RMNCAH indicators for the planning and monitoring of RMNCAH programs, and provide the denominators for accurate measurement of immunization coverage rates.

Current state of CRVS & health systems interoperability

P4. Challenges and opportunities afforded by interoperability (Nadya Kassam, UNICEF)

- In approximately 20 countries, children without birth certificates cannot be vaccinated and in more than 30 countries are unable to receive treatment at a health facility. In addition, there is a higher risk of statelessness for children who do not have a birth certificate and therefore no proof legal identity to prove nationality.
- Barriers to birth registration include registration costs (direct and indirect); limited knowledge of the importance on the part of parents, leaders, and officials; access and distance to civil registration facilities; low parental literacy and education; limited human resource capacity of registrars; discriminatory laws and policies, and limited investment. In addition, many settings face collapsed infrastructure due to conflict or disaster, the opportunity costs of travelling to register, bribes, and traditions such as naming ceremonies that cause delay and inaccuracies.
- The infrastructure of health systems, that cover the majority of the population in even in States with extremely poor CRVS, there is a real opportunity to dramatically improve birth registration. Innovation in both technology and process is key to reach the poorest and most marginalized, for example, Mobile Vital Records Systems use internet connected computers in hospitals and local authority offices to register births or mandating different cadres of workers to act as notifiers or registrars.

P5. Strengths and opportunities for improving CRVS systems (Adam MacNeil, CDC)

- Immunization is a potentially valuable focus for improving CRVS systems due to its position as a preventive, public health intervention and multiple information system opportunities consistent with other public health areas of focus.
- At country and subnational levels, immunization data are used for performance monitoring, to guide planning and finance and for logistics purposes. At the individual level, data are used for schedule monitoring and for identifying un- and under-vaccinated children. The challenges are to accurately count numerators (numbers of children vaccinated) and denominators (target population of eligible children).
- Currently, immunization coverage reporting is based on aggregated data, with target populations based on census projections, and there are limited operations linkages with other information systems. In the future, the aim is to build immunization coverage reporting on the basis of individual level data feeding into aggregate systems, target populations based on individual level data, and interoperability between health and CRVS systems.

P6. Landscape analysis of health & CRVS interoperability (Maria Muñoz, UNICEF)

- When working together, health programs and CRVS systems can create important mutual benefits, with the health sector contributing to the identification, reporting and registration of births and deaths and causes of death, both in facilities and at community level. In return, the CRVS system can generate data that can be analyzed and linked to health management information systems (HMIS) to underpin program planning, implementation and monitoring.
- A landscape analysis was undertaken to capture country specific information on contributions of the health sector to official birth and death registration processes, and to map UNICEF Country Office activities in birth registration/CRVS, with a focus on cross-program collaboration to improve birth registration/CRVS systems. Topics covered included the notification, registration, certification nexus; the official roles of various stakeholders; sharing of notification, registration and certification information; and

examples interoperability between health and CRVS.(that is, ways that Health and CRVS sectors work together).

- The single most significant findings were that is much scope for and need to improve collaboration across CRVS and health programs; and many opportunities for strengthened joint: advocacy and fundraising, programming, capacity building and planning and monitoring/interoperability of information systems, to enhance the scale and reach of CRVS and strength of health systems

P7. CRVS in child friendly communities in WCAR (Alain Prual & Andrew Brooks, UNICEF)

- By 2030, in the West and Central Africa Region (WCAR), more than half of all children under age five will not have had their births registered in unless there is significant improvement. Millions of children are at risk of being unable to complete their education, be forced into a child marriage, or be treated as adults within the criminal justice system.
- In several WCAR countries, the coverage of institutional births exceeds the birth registration rate. Whereas some countries (e.g. Cameroon, Ghana, Nigeria and Senegal) have similar levels of institutional delivery and birth registration, others such as Democratic Republic of Congo and Guinea-Bissau have levels of institutional births far higher than birth registration. This represents a missed opportunity for increasing registration rates within health facilities in WCAR.
- Routine immunization services and campaigns reach out to a large cohort of children under age 1 or under age 5 to reduce child morbidity and mortality. Effective planning of these health interventions requires age-specific, geographical data on numbers of eligible children. A functional CRVS system is best placed to provide such data.
- Child-centered approaches along the continuum of care, whereby birth and death registration is linked to health services include; placing registration offices within health facilities; mandating other cadres of workers (social workers, case workers, CHWs, midwives etc.) to notify or registrar (where the law allows for this) births and deaths. Using immunization services as entry points for birth registration; incorporating birth registration into immunization campaigns and Child Health Days; engaging community workers to create awareness on the importance of and process for registration.

Strengthening linkages between immunization and CRVS systems

P8. Linking immunization & CRVS (Anita Samuels, CDC)

- There are many potential benefits that accrue from linking immunization activities to CRVS. Each is a contributor to the other's information and data and there are opportunities on both sides for more complete reporting, for example through mobile data capture for unreached or under-reported populations, and linkages between immunization registries and CRVS.
- In practice, however, there are technical and political challenges that need to be addressed. Programs and their associated data systems are often created and funded in silos, have different programmatic outcomes, legal responsibilities and training, and diverse approaches to innovation, for example paper versus electronic systems. There is widespread evidence of reticence to collaborate between stakeholders; challenges associated with the particular legal requirements of CRVS systems, and problems of internet connectivity.
- On the other hand, there are good examples of creating a common data warehouse or other methods for exchanging data between systems, as well as institutional agreements for data sharing between different Ministries. Governance of shared data should address

issues of confidentiality, data access, sustainability, human resource capacities, legacy data transition, and funding across program silos.

- Opportunities include the use of immunization registries that capture information from vaccinations given within 24 hours of life; mobile population outreach; and registration of infants missed within the 30 day window for birth registration through immunizations given within the first few weeks of life.
- Better estimates are needed of target population and it is important to move away from the use of census projections to actual, real-time population data, tracking children across multiple health facilities, monitoring equity of coverage and identifying underserved populations.

P9. Population data for denominators (Mamadou Diallo, UNICEF & Adam MacNeil, CDC)

- Population data are required for RMNCAH programs for program planning and implementation, tailoring interventions to needs, and managing stock and supply levels. In addition, population-based statistics are essential for monitoring the SDGs and other health goals and targets.
- However, population-based data are often unreliable, especially at local levels, with incomplete reporting of births and deaths, challenges of internal and external migration and population mobility, and security issues.
- There are potentially many sources of population data, including CRVS, health facility data, censuses, and statistical models largely developed at global levels. While the latter may be sufficient at national and regional levels, they rarely capture the specificities of local communities and sub-district areas.
- Research is currently under way on the potential to use CRVS and other health registries as the basis for population counting; and to build local best practices and innovative solutions to reach populations excluded from the CRVS and related systems.

P10. Immunization registers & CRVS in Latin America (Gabriela Felix, PAHO)

- In the Latin America region, there is growing experience in the potential of electronic immunization registries (EIRs) that bring together in electronic format confidential, population-based records, the outputs of which facilitate coverage monitoring by vaccine, dose, geographical area, age and provider, thus supporting individual (and timely) schedule follow-up. EIRs that are linked with civil registrars can provide an opportunity to strengthen the completeness of both as demonstrated in Uruguay and Bogota
- A recent review of lessons learned with regard to immunization registries concluded that participation of various stakeholders and close monitoring of progress are essential for success. Commitment from the health authorities is essential and it has to be sustained over time because an EIR requires sustained financial and human resource investments.

P11. Using immunization strategies for birth registration in Kenya (Brian Munkombwe, CDC)

- A demonstration project located in Homabay County, an area of Western Kenya that has very low birth/death registration coverage (< 30% in 2012) is underway. The project aims to test and evaluate procedures to improve birth and death registration and certificate services; improve quality and completeness of vital statistics, including cause of death information and serve as a model to expand improvement activities to other counties in Kenya.
- Interventions include sponsored sensitization and training workshops for birth notification directed to MCH workers, CHWs, religious leaders, assistant chiefs, health departments, and community radio programs. A monitoring plan includes assessment of the MCH strategy for notifying community births to the registration authorities, and provision of

information for corrective action as needed.

- Initial results indicate a significant increase in birth notification, with over 90% of health facilities with MCH services notifying births and a decrease in backlogs of non-transmitted forms.

P12. Gavi priorities around CRVS and immunization (Chung Won Lee, Gavi)

- The goals of Gavi, the Vaccine Alliance(Gavi) include supporting countries to achieve measurable improvements in the availability, quality, use and transparency of data and enable countries to use data to improve immunisation coverage and equity. To these ends, Gavi is supporting five priority areas: to improve immunization coverage estimates; improve estimates of target populations; strengthen registries and facility information systems; enhance workforce and management capacity and motivation; and support countries to assess, learn and improve.
- A major challenge for Gavi is that official denominators to calculate vaccine coverage are often inaccurate. over- or under-estimated. For example, the total number of children vaccinated with BCG and Penta 1 is higher compared to the number of target live births and children under 1 year-age, respectively. Furthermore, officially projected target population data are generally not available at the facility and community level.
- In response, there are multiple efforts to generate more reliable denominator data (P9). These include, data on children less than one year old collected by immunization campaign teams; microplanning data for routine immunization planning collected by immunization teams; and aerial satellite imagery for selected areas. As a result there may be multiple different denominator data sources posing challenges for their use. In Afghanistan, for example, there are six different denominator data sources currently being used.
- Important outstanding issues that need to be clarified are potential measurable outcomes of investment in CRVS at global, regional and country levels; a set of concrete communication messages on CRVS in terms of what to expect from global/regional level activities; and recommended actions at country level.

Day 2: Pregnancy tracking and other RMNCAH opportunities for CRVS

P13. Using pregnancy registries to strengthen CRVS (Garrett Mehl, WHO)

- Digital reproductive and pregnancy registries are at a mature state and are being integrated and made interoperable with other national HIS systems. Accurate measurement and effective accountability requires strong integrated information systems, driven by country needs and uses.
- Paper registrar systems are sub-standard due to the limited access to and usability of resulting data. Paper records are easily lost or destroyed in an emergency and are difficult to replace. Data collected is often not used to guide health workforce point of care service provision, or decision-maker supervision or planning. Statistical modeling and data estimations are used to fill in information gaps for planning and decision-making.
- Priorities actions include the standardized data elements, indicators, and reporting frameworks; use of unique identifiers linked to records that are consistent throughout the continuum of care; systematic and routine screening for identification of disease states and life stages, and mechanisms or referral; consistent user interface elements across deployments facilitating replicable training methodology approaches.

P14. Maternal Perinatal Death Surveillance & Response (Natalie Roos & Nancy Kidula, WHO)

- Maternal Perinatal Death Surveillance & Response (MDSR) is a continuous action cycle that links the health information system with quality improvement processes. The essential key steps in MDSR are identification and notification of maternal deaths, reviewing the causes and contributing factors that lead up to the dead, formulating recommendations and actions to prevent future similar deaths and follow up on the recommended actions ensuring they are acted upon.
- If well integrated, MDSR can help to strengthen CRVS systems and better track maternal mortality ratio. It also helps to improve the quality of care and how to measure quality of care improvements.
- MDSR related policy have gained much uptake among member states in low/ and middle income countries. However implementation to a fully functional MDSR approach still remains weak in many countries.
- To address the need for more attention on perinatal mortality prevention, WHO has published a classification system (ICD-PM) for perinatal mortality that is applicable across different settings with different diagnostic capabilities. Also a guide for conducting audit and review of perinatal deaths has been published to increase awareness around perinatal deaths and a framework to assess the burden and create strategies for prevention.
- Filling out death certificates needs to be strengthened and routines for reporting deaths to the CRVS system needs to be standardized.

P15. Pregnancy registration and SMS in South Africa (Chris Seebregts, Jembi Health Systems)

- MomConnect enables pregnant women to use mobile phones to register pregnancies in the public sector. Once registered, each mother is sent stage-based messages to support her and her baby. More than 1 million pregnancies have been registered from all locations in South Africa in the first two years of operation of MomConnect, which represents between 50% and 60% of all pregnancies expected in the public sector over that time period.
- Technical Specification of MomConnect are based on international standards, profiles and interoperability specifications. The application has an interoperability architecture with Health Information Exchange, demographic and clinical registries. It also includes a unique person identifier and identification system.
- Challenges include: Legal and governance frameworks; privacy; limited infrastructure and connectivity; human resource capacity.
- Extending to Continuum of Care and CRVS: The Architecture, processes and technologies covered by health platforms, such as MomConnect could be extended to offer support for CRVS. Integration of well-structured event data can be used to create a longitudinal shared life record between health and vital events. Data triangulation between health and civil registration systems will improve data availability and quality for both systems.

P16. BID Initiative to improve CRVS and Immunization in Tanzania (Hassan Mtenga, PATH)

- Immunization coverage in Tanzania was reported at 97% in 2015. However challenges such as inaccurate denominators, difficulty tracing defaulters, lack of unique identifiers for infants, poor data visibility, and complexity of data collection forms, as well as reaching hard to reach, nomadic and remote populations still remain. The BID initiative in Tanzania aims to improve immunization data quality and availability, improve

coverage and access for hard to reach populations, increase data use and decision skills at all levels of health system, and increase capacity to monitor performance.

- The Electronic Immunization Registry (EIR) aims to link and enable data sharing between MNCH and immunization services by accounting all births in health facilities and linking the information to immunization clinics for service delivery. For remote health facility deliveries, a SMS based application is used by community health workers and or village chairman to notify home deliveries to nearby health facility for immunization series.
- Birth certification coverage in Tanzania lags significantly behind immunization coverage at 11%-16% while immunization coverage reported at 97% in 2015. In order to increase birth registration and certification coverage, RITA, a CRVS authority in Tanzania, in collaboration with Immunization program in Tanzania is in the process of linking the EIR with CRVS birth registry. Other activities are; including a minimum data for birth notification, modalities to implement National ID as child unique ID when registering a child, collaborating with community birth notifications, and developing a strategy for decentralization of birth registration and certification to the ward level.

P17. Opportunities for Improved Health & CRVS in Bangladesh (Kelsey Zeller, Johns Hopkins)

- In Bangladesh the rates of home deliveries are high and utilization of antenatal and postnatal care is low. Challenges include a lack of consistent denominators, absence of systematic pregnancy surveillance protocols or tools, and first ANC visits being delayed due to late detection. There are no reminders to client or worker, no detection of missed visits, no systematic, reliable supervisory data, and no birth notification system to trigger ENC.
- Several mobile health technologies have been tested and deployed in country; (i) mLABOR system dispatched trained emergency obstetric nurses to home-based deliveries after 90% of families sent a notification (ii) mCARE which allowed for client driven birth and labor notification in real time through Rapid Pro and provided systematic enumeration, follow-up and prioritization tools to workers on OpenSRP. This tripled ANC and doubled PNC in rural Bangladesh; (iii) mTika has also been shown to improve timely vaccination and increase coverage after use by government health workers using similar strategies to mCARE.
- OpenSRP is an open source, customizable digital platform that allows frontline workers to digitally register and track the health of their entire client population through a unique health ID. It also supports data sharing between workforces in the same catchment area and reduces duplicated work. It can be linked with other digital platforms such as Rapid pro, OpenMRS and DHIS2. Deployments in Bangladesh include RMNCAH Registry, Immunization Registry, and a CRVS component is in development to allow for birth and death reporting.

P18. Global Financing Facility for CRVS (Irina Dincu, CRVS Centre of Excellence)

- The Global Financing Facility is a multi-stakeholder partnership that supports country-led efforts to improve the health of women, children, and adolescents by; (i) acting as an innovative financing pathfinder to accelerate the efforts to reach the 2030 goals for women's, children's, and adolescents' health; (ii) financing high impact, evidence- and rights-based interventions to achieve measurable and equitable results; (iii) building inclusive, resilient systems and increasing domestic financing over time to sustain the gains and ensure that all women, children, and adolescents have access to essential healthcare, contributing to universal health coverage; (iv) filling the financing gap by

mobilizing additional resources from public and private sources, both domestic and international, and making more efficient use of existing resources.

- There is a US\$33.3 billion funding gap (2015) for RMNCAH in high-burden, low- and lower-middle-income countries.
- The GFF focuses on 63 high-burden low- and lower-middle-income countries. National governments lead the process with the involvement of the broad set of RMNCAH stakeholders involved in the RMNCAH response coordinated through a country platform.

P19. Saving & improving the lives of women & children (Chunmei Li, Johnson & Johnson)

- Johnson & Johnson (J&J) works with partners and supports programs that are saving and improving the lives of women and children. Since 2010 J&J has invested over 200 million towards efforts in line with the Every Woman Every Child movement.
- The Helping Babies Breathe (HBB) initiative trains health care workers in low-resource settings to intervene when newborns have birth asphyxia, the inability to breathe at birth. HBB is committed to increase the availability of skilled birth attendants at every birth. Nurses and midwives with HBB training have the skills to resuscitate over 90% of babies with birth asphyxia.
- Through mobile platforms such as mMitra, a program that sends pregnant women and new mothers voice messages twice a week that provide preventive care information (correlated to their child's age and development) directly to their mobile phones, promoting positive and health behaviors in low-income urban communities across India. In South Africa MomConnect messages are designed to build an emotional connection with mothers, encouraging and empowering them to take an active role in their healthcare, while providing advice on the importance of attending antenatal visits, how to prepare for a healthy and safe labor, and the best ways to take care of their newborn.

Day 3: Strengthening CRVS through health facility data

P20. Opportunities for DHIS2 (Maria Muniz, UNICEF)

- District Health Information Software 2 (DHIS2) is a flexible, web-based open-source information system that supports the capture, management, analysis, visualization and communication of information; assisting governments and organizations to manage their operations more effectively. It has been field-tested and continuously improved for over 15 years, and implemented in over 50 low-income and middle-income (LMIC) countries. It is a flexible data platform equipped with configuration and customization for a range of organizations and use cases. Mobile solutions are supported and interoperability with other systems through Web APIs. It is used by ministries of health as a national health management information system software, and has also been adopted for education, WASH, nutrition and other sectors in some countries.
- DHIS2 supports management of aggregate data, allowing for configuration of data elements, data entry forms, validation rules, indicators and reports as well as data visualization through maps, charts, pivot tables and dashboards.
- DHIS2 also supports the collection, management and analyses of transactional, case-based data records, allowing tracking of these persons over time using a flexible set of identifiers (e.g. tracing persons enrolled in programs across facilities to reduce drop-outs). It can capture information about anonymous events (e.g. cause of death reporting) and cases (e.g. line listing/anonymous in-patient admission information).

P21. Innovation for cause of death modules for HMIS (Anneke Schmitter, WHO)

- There are many challenges with capturing cause of death in health facilities including non-standard medical certificate of cause of death and no validation routines to check for

basic errors. The International Statistical Classification of Diseases and Health Related Problems (ICD) has 15,000 codes of which 11,000 are underlining causes of death.

- To help overcome these challenges, the START-UP Mortality List was developed in 2015 by WHO and provides a framework and design which is consistent with ICD-10. START-UP has only 106 causes + 17 optional subcategories which focus on causes of death and simplified set of rules for underlying cause. It is intended for initial use in low resource or decentralized settings and can be scaled to the full ICD. It is a first step towards standardized reporting of causes of death which can be used to inform setting public health priorities.
- There is an opportunity for a vital events module to be developed for regularized, standardized data for recording births and death notifications in health systems for CRVS.
- New approaches to mortality data in countries may require supplementary consideration as part of existing CRVS system assessments.

P22. Lessons from record-linkage at Statistics Canada (Abel DaSylva, Statistics Canada)

- Statistics Canada is a centralized agency with rigorous policies on administrative data and record linkage. Statistics Canada influences, has access to and makes maximum possible use of administrative and alternative data in its statistical programs, resulting in reduced response burden, lower costs, improved quality and new data series for users, while maintaining public trust.
- Current applications of the data include; (i) analysis, such as linking the Canadian Community Health Survey and the Canadian Mortality Database for survival analysis; (ii) direct estimation, as demonstrated in the Canadian Statistical Demographic Database research project, including links to births; and (iii) operational use through maintaining a sampling frame or data replacement as when linking the census to tax files for income data.
- Data sources come from several sources such as; survey data, administrative data from tax, vital statistics, and health; big data are also being explored including data from financial transactions, sensors and scanners and public utilities.

P23. Rapid SMS, health and CRVS collaboration in Senegal (Laetitia Bazzi-Veil, UNICEF)

- Senegal has a favorable context for strengthening links between health and CRVS systems do to the high institutional birth rates (76.9) and number of pregnant women who have at least two antenatal care visits (90.1%). The government has made national commitments in line with the African Union CRVS Initiative and Civil Registration was recognized as a national priority in 2015.
- Joint planning and funding between Child Protection & Health sectors strengthen collaboration and build on each sector's comparative advantages. Cross-sectoral advocacy & technical support at a strategic level is needed to move forward interoperability (evidence based, sectors policies planning & systems building) between sectors.
- Between 2014 and 2015 birth registration rates in Senegal rose from 73% to 80% respectively. Several interventions and processes were utilized to contribute to the increase in registration such as placing civil registry desks within health facilities, integrating birth registration into child health booklets, Child Health Day campaigns. In addition, utilizing health workers to notify, promote and track birth registration as well as utilizing social workers to facilitate the late registration process for children who are beyond the legal deadline.

P24. Partnerships for better CRVS data in Ghana (Ashley Frederes, Bloomberg Philanthropies)

- Fragmented/siloed processes among major CRVS stakeholders (Births and Deaths Registry, Ghana Health Service and Ghana Statistical Services), lack of incentives to obtain birth/death certificates, and lack of requirement for birth/death certificates to access key social and public health services results in under-registration of vital events and poor quality and representativeness of cause of death data.
- The country strategy with D4H supports an integrated approach which applies a systems focus using business process mapping to improve intra- and inter-agency processes and incorporate into revised SOPs to; (i) link DHIS2 and CR to increase notification of births and deaths, (ii) require health facilities to report in-facility vital events directly to CR (iii) design notification steps and forms for community deaths.
- The objectives include; (i) to improve the completeness and quality of facility-based mortality data through national rollout of DHIS2 and adoption of updated international standard form of death certificate (ii) to improve the completeness, quality and representativeness of COD data through application of verbal autopsy (WHO 2016 form) for community-based deaths, (iii) to use BPMs to link notification and VA, (iv) to conduct legal and regulatory reviews to determine implications of national rollout of VA and integration with CRVS system (underway – results expected January 2017).

P25. Beyond health & CRVS: Linking IDs and broader systems linkages (Lori Thorell, UNICEF)

- Data on women and children is often fragmented and held in information silos. In health systems, records are often kept in manual registries, child health books, or logbooks managed by different departments or facilities. In lieu of fully functioning CRVS systems, the adoption of unique health IDs is an important interim step to better monitor health outcomes for women and children. Unique health IDs provide the ability to measure and account for health outcomes of a person over time and across multiple health systems.
- The Open Health Information Exchange is an open source architecture to support information exchange and interoperability for systems and devices to exchange data across multiple points of care and service delivery. The Client Registry/Enterprise Master Patient Index (EMPI) supports the unique identification and management of patient identities. This approach provides the necessary digital foundation to connect data between RMNCAH services within the health system.
- In Asia and the Pacific, the regional AeHIN Community of Interoperability Laboratories (COIL) were launched by development partners to mitigate investment risk on national-scale digital health deployments, support capacity-building in health ICT; and serve as a catalyst for innovation by the private sector actors in national care delivery networks.

P26. Bloomberg Philanthropies: Data for Health (Jennifer Ellis, Bloomberg Philanthropies)

- Gaps in comprehensive national birth and death data systems, make it difficult for public health leaders to address urgent health challenges. Without accurate data, governments are unable to make informed decisions about public health priorities and programs, but this is a problem that can be solved. Roughly two-thirds of all deaths globally are not registered or certified. Out of the total certified deaths, about three-quarters lack a specific cause of death, meaning that public-health leaders often don't know what diseases people may be dying of prematurely.
- To address this, Bloomberg Philanthropies and partners support Data for Health, a \$100 million initiative that will enable 20 low- and middle-income countries to vastly improve public health data collection.
- The first year of was focused on developing country driven work plans which identified specific, ambitious, scalable, early impacts over a 3-4-year timeframe. Country level

progress to date include; (i) new mechanisms for collecting data on out-of-hospital deaths in Myanmar, Rwanda and Tanzania, (ii) journalist trainings in Brazil on data use and (iii) new mechanisms for using data in Shanghai and Philippines.

P27. CHAMPS/COMSA Mortality Surveillance (Tamar Farag, Bill & Melinda Gates Foundation)

- The Bill & Melinda Gates Foundation funds the Child Health and Mortality Prevention Surveillance (CHAMPS) network, which is a long-term collaborative program to track the causes of childhood mortality. CHAMPS will catalyze global health policies, research, innovation and other actions by providing better data about how, where and why young children are getting sick and dying. CHAMPS program will be informed through extensive socio-behavioral, participatory engagement with communities, including sensitization on CHAMPS procedures.
- CHAMPS will systematically identify and document the causes of under-five mortality at sites across South Asia and Sub-Saharan Africa with the aim to capture both perinatal and childhood causes of death from infectious and noninfectious causes. A special emphasis will be placed on identifying and classifying stillbirths and neonatal deaths, which will require special attention towards prioritizing and identifying pregnant women. CHAMPS will determine the cause of death through minimally invasive tissue sampling (MITS), which was developed to reduce the uncertainty regarding causes of death in low- and middle-income countries. The procedure involves collecting tissue specimens from a predefined set of organs, which are then examined through histopathologic, microbiologic and molecular investigations.
- The Countrywide Mortality Surveillance for Action (COMSA) initiative is a sample registration system (SRS)-based approach that will venture outside CHAMPS sites to collect mortality data across a country. COMSA will be conducted by and for country statistical and health authorities to ensure long-term sustainability. To promote and strengthen CRVS, COMSA staff will ensure vital events detected are translated into registrations and certifications through integration and reporting with e-CRVS systems. Through integration with CHAMPS, COMSA will propagate high quality data about causes of death across the map. The first COMSA country will be Mozambique. A second country will be added in early 2017.

Reaching hard to reach & vulnerable populations

P28. Including vulnerable populations within CRVS systems (Kristen Wenz, World Bank)

- Vulnerable and hard to reach populations are most likely to be left out of CRVS systems. Many vulnerable populations live in informal settlements, institutions, or remote areas and are often missed by DHIS, censuses and other household surveys.
- Leaving vulnerable populations out of health and CRVS systems does more than create inaccurate population estimates, it violates the rights of individuals and perpetuates intergenerational cycles of poverty and inequality.
- Taking a multisector approach to tackling multiple deprivations that vulnerable populations face is their only way to make a lasting impact.
- Ensuring national laws guarantee against racial and gender discrimination; improving the availability and quality of data; and expanding efforts to measure disparities for the most vulnerable and hard to reach populations is critical to achieving equitable development and reach every woman, every child and every adolescent.

P29. Information management system for orphans & vulnerable children (Christine Fu, USAID)

- The US President's Emergency Plan for AIDS Relief (PEPFAR) supports the Orphans and Vulnerable Children Longitudinal Management Information System (OLMIS) in Kenya. This is a reporting system that enables organizations to capture and manage data on thousands of children. It tracks all of the services received by each child over time and produces real-time information to assist in procurement of commodities.
- The OLMIS also collects data on children who may receive birth certificates, but because data entry is manual there are significant delays in reporting, resulting in many births not being included in the civil registrar. Previously, OLMIS and CRVS systems were not linked in Kenya and there was no data sharing or interoperability. An innovative approach is now being introduced to ensure interoperability between CRVS, OLMIS, and child protection systems and the Integrated Population Register.
- Opportunities to strengthen linkages between CRVS systems and child welfare interventions such as OLMIS include establishing interoperability and data sharing between government ministries and departments; investing in national register systems; and providing resources to support CRVS data privacy, management, validation/analysis and dissemination.

P30. Homebased records: Opportunities for immunization & CRVS (Richard Duncan, UNICEF)

- A home based record is a medical document issued by a health authority that records a person's history of vaccinations and may mirror facility-records/central registers. They are often referred to as vaccination cards, child-health books, baby books, immunization passports.
- Home-based records can play a critical role in vaccine service delivery by facilitating caregiver awareness, coordination of care, and accountability of health workers for immunization practices. Some of the challenges are; lack of supply and incomplete records by health workers and caregivers.

P31. Enabling communities to scale CRVS (Babatunde Fakunle, CHESTRAD)

- At the community level there are both challenges and opportunities around increasing CRVS coverage. Limited awareness; cultural practices that are not in line with registration laws (naming traditions or religious ceremonies); cost and accessibility to registration facilities limit the demand for registration. There are also many opportunities to scale coverage of registration through harnessing innovative solutions to help overcome the demand barriers can greatly increase converge of services.
- Civil Registration and Vital Statistics for Accountability and Performance (ViSAP) is an innovative solution to address demand barriers within the community. ViSAP has three components; (i) I-Registered which is an advocacy strategy to increase political commitment, community awareness, funding and multi-sector coherence for CRVS; (ii) Tech-CRVS for data interoperability, improved infrastructure, and human resource capacity; (iii) E-CHRP to strengthen linkages between CRVS and health systems and to track health outcomes across the continuum of care leading to better monitoring and planning.

Synthesis of meeting findings

Innovation & opportunities: CRVS and the continuum of care

Over the past several decades, the health sector has forged a widespread network of health facilities and community health workers that seeks to reach communities everywhere, from urban slums to remote rural and marginalized populations to deliver key public health interventions. There is a growing realization that this offers a vast untapped potential to leverage health sector programs, services and interventions – for example immunization and maternal-newborn health care – for the notification and registration of births and deaths, and improved recording of causes of death (P1).

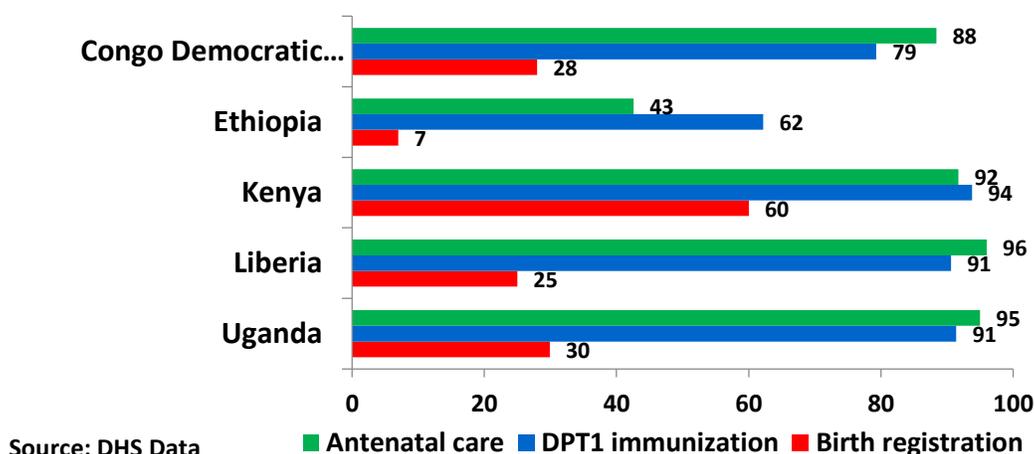
This potential resource for increasing the coverage of birth and death registration has remained largely untapped so that despite an overall rise in birth registration levels over the last 15 years, not all regions have made significant progress (P2). Globally, of all infants worldwide, around 1 in 3 does not have their births registered; practically all of these unregistered infants live in either sub-Saharan Africa or Asia. Deaths among infants and women of reproductive age are even less likely to be officially registered, resulting in loss of information that is essential for RMNCAH policies and programs.

Experience is accumulating from countries and partners on how to exploit linkages across CRVS and health systems to the benefit of both. Innovative new approaches applied as part of health programs, including digital tools and analytics, have the potential to rapidly scale up the notification and registration of births and deaths and to improve the availability and quality of vital statistics that are essential for program planning and monitoring. This report summarizes some of these innovations and lessons learnt from countries and partners around the five thematic areas.

Interoperability between CRVS and the RMNCAH continuum of care

In almost all settings, birth registration coverage (percentage of children under 5 whose births are registered by civil authorities) lags significantly behind key RMNCAH indicators such as coverage of antenatal care (percentage of pregnant women with at least one visit); and DPT1 immunization (percent of children aged 12-23 months who received the first dose of DPT) (see Figure 3, P3). Furthermore, coverage of birth certification is frequently considerably lower than notification rates, indicating leakages of information between the notification and registration steps of the civil registration process.

Figure 3. Comparison of coverage of ANC, DPT1, and birth registration²⁸ (P3)



Health sector interventions, particularly for maternal health care and immunization, offer multiple opportunities to strengthen the notification, registration and certification of births and deaths by:

- Creating awareness of the importance of registration during antenatal and delivery care;
- Ensuring that all births that occur in health facilities are immediately notified to the civil registrar (including co-locating registration facilities within hospitals);
- Notifying home births that occur with the assistance of skilled birth attendants;
- Cross-checking vaccination cards/MCH booklet for birth notification/registration during immunization visits for DTP1, DPT2, DPT3 & measles containing vaccine (MCV);
- Notifying unregistered home births when presented for immunization and other RMNCAH services;
- Community outreach for creating demand for birth and death registration and sensitizing RMNCAH service providers and skilled birth attendants on registration of births and deaths;
- Strengthening maternal death surveillance and response system (MDSR) for death registration and causes of death;
- Ensuring that birth and death notification forms submitted from the health sector include key information items required for the registration process, including unique ID numbers where available to the civil registrar.²⁹

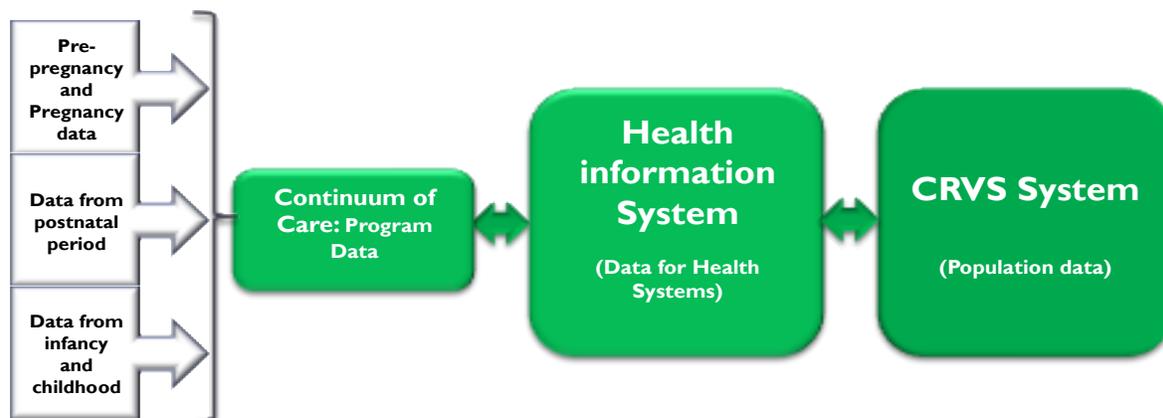
These interactions between health services and CRVS can be summarized as health system and CRVS *interoperability*, whereby civil registration services are offered together with health and other government services (P4). A general definition of interoperability is the extent to which systems and devices can exchange and interpret shared information. The fundamental basis of interoperability is harmonizing the context with which information is collected so that it is broadly reusable by a much larger set of stakeholders. The concept acknowledges the autonomy and independence of each sector and entity, including in the setting of policies, priorities, and authority over their respective area of responsibility (P1, P4).

Interoperability is most effective when there are mutual benefits for all stakeholders (Figure 4, P1, P4). The reach of health sector programs, services and interventions can be leveraged to ensure notification of births and deaths are sent to the civil registrar for registration and certification, and can improve recording of causes of death. When the national ID agency is linked to the CRVS or health system, ID numbers issued at birth can be included in death registration. Thus data linkage across maternal and child health RMNCAH interventions is enabled, greatly improving analytical capabilities and permitting the identification of births or deaths missing (or duplicated) from a single register. Accurate data from the civil register that is shared with the health sector ensures better targeting of services and enables evidence-based policy making and planning. Mechanisms and policies should be put in place for effective communications between health workers and local registrars, enabling immediate notification and registration for all births taking place in health facilities.

Despite the potential benefits to both sides, achieving interoperability is not a simple matter. Country experiences shared at the meeting, including in Bangladesh (P17), Ghana (P24), Kenya (P11, P29), South Africa (P15), Tanzania (P16) and countries in the West and Central African Region such as Benin, Chad, Mali and, Senegal (P23) and Sierra Leone (P7), describe some common challenges but also offer instructive lessons learnt and ways forward (P7). Challenges encountered include, for example, legal and governance frameworks that are not supportive of data sharing and interoperability; public concerns about data privacy and security and patient confidentiality; inadequate ICT Infrastructure (computers, phones) and connectivity (reach and cost); issues of server hosting and data curation; and limited human resource capacities and skills.

Figure 4. The CoC from program data to population data through CRVS systems (P1)

Strengthening Data



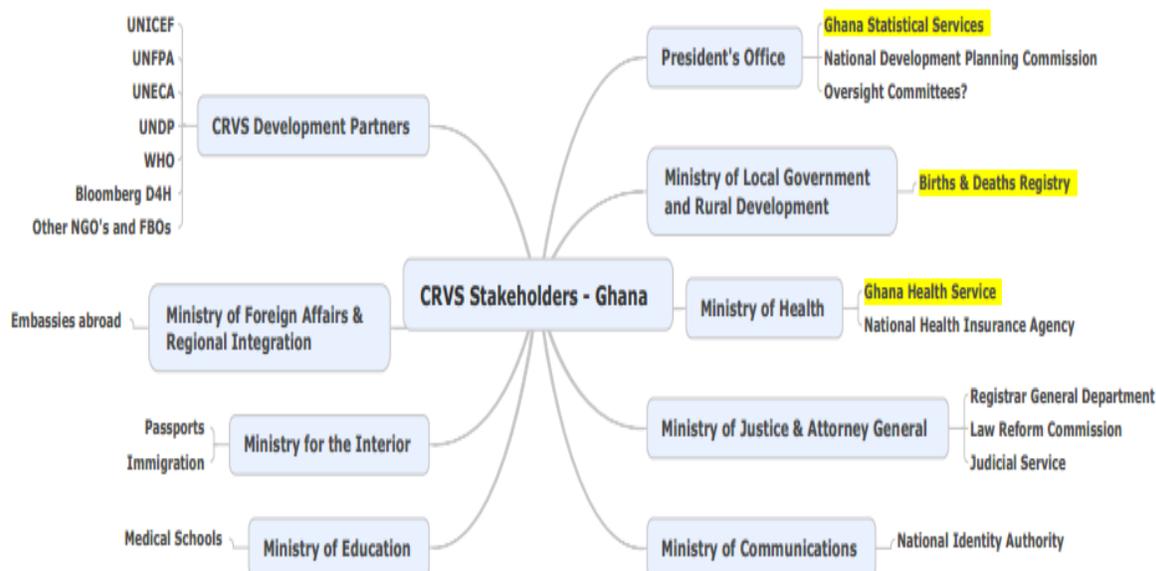
Achieving CRVS/continuum of care interoperability has implications for the way RMNCAH data is collected, analyzed and shared. These include the need to:

- Develop digital solutions with government partners in the CRVS and public health system working together to produce an open architecture and vision to guide implementation and innovation.
- Shift from collection of aggregated episode-based data to longitudinal individual records that register all encounters with health services in real time and over time.
- Consistently use standards across data collection activities, both within health and with other sectors such as CRVS. Standards are also needed for data sharing and interoperability between data collection systems.
- Include unique identifiers in health and civil registration records to facilitate data linkage (P22).
- Establish mechanisms to ensure data privacy and confidentiality, while enabling data sharing across systems for analytical and public health purposes.

Overcoming the challenges to interoperability will require bringing together CRVS and health systems stakeholders in a shared exercise to better understand how the CRVS system works and the possible entry points for the health sector, particularly in relation to the notification of a birth or death and ensuring that each notified event is officially registered (Figure 5, P24). Stakeholder analysis and detailed process mapping of the CRVS system is a necessary prerequisite for successful interoperability. However, in many countries, the involvement of women's and children's programs such as RMNCAH and immunization has so far been limited. Efforts to promote interoperability will also be greatly strengthened by the development of an open-source, standards-based, freely available alternative to homegrown solutions and proprietary CRVS packages, promoting interoperability and a rights-based approach.³⁰

Figure 5. CRVS stakeholder analysis in Ghana, 2015 (P24)*

*Highlighted text indicates major stakeholders in Ghana CRVS system development supported by the Data for Health Initiative.



Strengthening linkages between immunization and CRVS

Immunization data systems have tended to focus on counting vaccines delivered but they also need reliable and complete data on the target population – total live births – at local administrative, district and national levels (P5, P8, P11, P12). Currently, there is a heavy reliance on estimating total births using projections from the most recent census. However, such projections are known to be increasingly inaccurate over time due to lack of frequency, migration, and missed populations such as nomadic or stateless persons or those living in informal settlements. Inaccurate data on total births is problematic not only for monitoring progress but also for logistical reasons, resulting in under- or over-supply of essential vaccines and commodities. Timely and complete registration of births would greatly benefit immunization programs by providing real-time and more accurate estimates of total births, thus enabling better targeting of commodities and saving resources.

Immunization information systems use coverage reporting from aggregate data and have limited operational linkages with other information systems within the health sector. What is needed to improve program delivery and effectiveness is a foundation of individual level data that feeds into aggregate reporting and calculation of target populations based on individual level data.

From the CRVS perspective, collaborating with immunization programs is a strategic way to increase birth registration rates. The immunization schedule commences shortly after birth and infants receive immunizations on approximately five separate occasions prior to their first birthday. This means that in principle, infants who have missed registration at birth could be registered shortly after, thus helping to ensure the accurate recording of key characteristics of the child and the timely issuance of a birth certificate. This is not only beneficial for the child and its family but is also important from a statistical perspective. Should the child unfortunately die, its death is more likely to be registered if its birth was registered, thus improving the coverage of death registration and child mortality statistics, particularly during the infant and neonatal periods.

The immunization schedule also provides several opportunities for health workers, who are administering the immunizations and running campaigns, to advocate for birth registration and

check whether or not the child has been registered and received a birth certificate. Combining efforts in immunization and birth registration would not only benefit national governments and increase birth registration coverage, but also benefit families by saving them money, time and opportunity costs involved in registration.

In many countries, health workers issue the child with a vaccination card, which could be adapted to include a space to mark whether the child was registered. With the increase in computerized immunization registries that include unique identifiers, health workers could also have the opportunity to make note of the child in an immunization registry while also notifying the civil registrar of the details of the birth.

Immunization also offers an opportunity to check for infants and children that have dropped out of immunization and seek to identify and register any deaths that may have occurred. In a number of African countries, including Chad, Democratic Republic of Congo, and Guinea-Bissau, high levels of BCG coverage coincide with very low birth registration rates. These are missed opportunities to link immunization programs with CRVS system improvements.

Despite the potential advantages of linking immunization and CRVS data, there are challenges to be addressed. Within the health sector, information systems are often created in silos and there are technical and political challenges in overcoming reticence to collaborate between stakeholders within health and with other sectors. Civil registration is first and foremost a legal and administrative system. Creating linkages with immunization programs affects health workers who might be expected to take on responsibilities that have legal and administrative implications beyond their traditional scope of work.

Effective linking of immunization and registration systems requires that the information collected by the immunization program be relevant and complete from legal and administrative perspectives. Immunization records are currently designed primarily to collect data used for immunization and other health purposes. For example, information needs for the registration of a birth include items not normally contained in the immunization record such as, names of parents, their ID numbers, and place of usual residence. It is, therefore, important to ensure collaborative mechanisms are in place for harmonizing immunization and registration records.

Notwithstanding such challenges, there are examples of progress, particularly in South America, where electronic immunization registries (EIRs) have been rolled out since 2008 (P10). Not to be confused with an immunization information system, the EIR is an electronic, population-based information system that gathers individual, confidential, vaccination data (doses given) from an entire country. It provides outputs to facilitate coverage monitoring by vaccine, dose, geographical area and age, and provides and supports individual (and timely) scheduled follow-ups.

EIRs are based on the assumption of a move from paper to electronic systems. This is only possible where there is sufficient Internet connectivity and bandwidth, then it is possible to create linkages across databases by mapping data elements and incorporating unique identifiers, and there is a common data warehouse for exchanging data between systems. Further issues for consideration include whether to opt for patented CRVS systems versus paper or open source software.

As with other innovations discussed during the meeting, it is vital to ensure that such efforts involve all stakeholders across health programs and with non-health sectors and the development of a customized enterprise architecture and business process mapping (discussed later in this document). In UR Tanzania, for example, PATH and the Immunization program are working with the national registration authority (RITA) and other stakeholders, to link the EIR with the CRVS registry (P16). This is part of a broader effort to decentralize birth registration

and certification to ward level while also incorporating the unique national ID number when the child is first registered at the health facility.³¹ Another example is the Open Health Information Exchange (OpenHIE), which can be used to establish a vaccination record in the immunization registry and associate the baby's vaccination card with the ID in the Civil Registry

Pregnancy tracking and other RMNCAH opportunities for CRVS

Increased attention to child health over the past decade has resulted in remarkable progress to reduce the number of child deaths worldwide. Nonetheless, far too many children, in particular newborns, continue to die each year. Moreover, it has proved difficult to achieve substantial reductions in maternal deaths in some settings. Globally, 303,000 women die during pregnancy and childbirth, 2.7 million newborns die during the first 28 days of life and 2.6 million babies are stillborn each year.³² Several initiatives to remedy this have already been mentioned and they share a need for reliable data on numerators – numbers of children or pregnant women and adolescents receiving interventions and numbers of maternal, newborn (including stillbirths) and child deaths. However, for the accurate calculation of coverage and mortality rates, it is essential to have reliable data on target populations – numbers of pregnant women, total live births and fetal deaths. Population data, especially at subnational or district level, are required for program planning and implementation, for example, tailoring interventions to the level of need and managing logistics, stocks and supplies. They are also essential for monitoring progress, using coverage indicators and impact indicators such as mortality and morbidity rates.

From an information collection and management perspective, the concept of the continuum of care represents a paradigm shift away from counting individual events (such as antenatal care visits, women delivered or immunizations given) towards data collection across the continuum of care over time, across different services and service delivery points. This has a number of implications, including the need to:

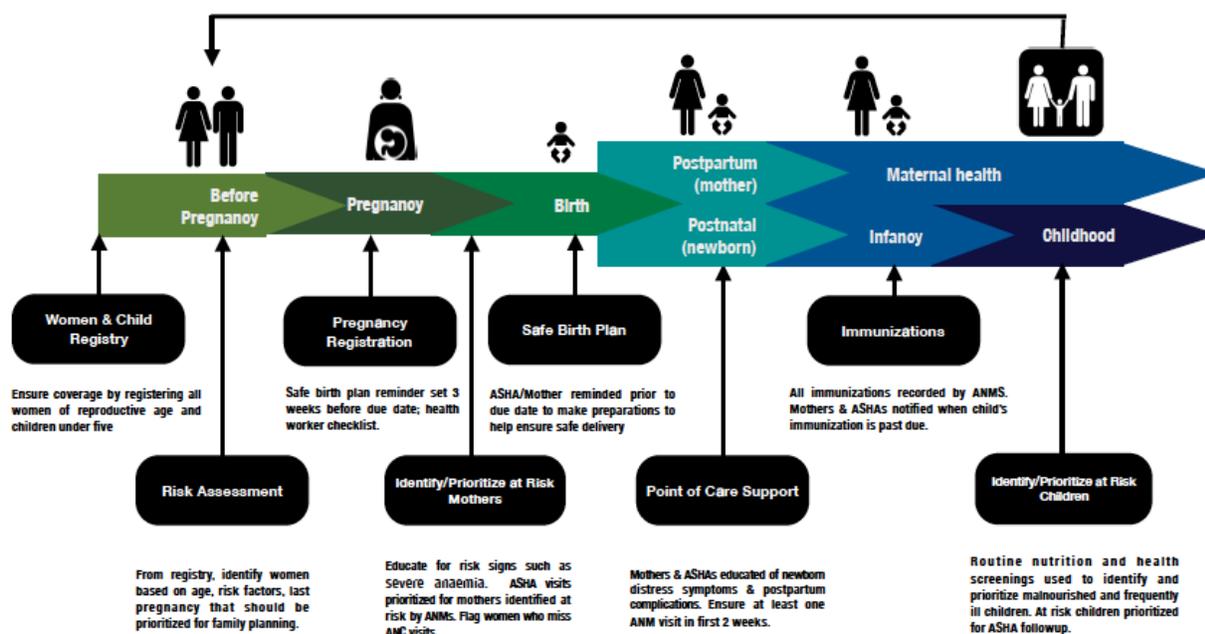
- Share data standards across the interventions along the continuum of care, for both women and infants from pre-pregnancy through early childhood;
- Link individual records over time and across interventions through a unique ID that is allocated at birth for infants;
- Establish data architecture, infrastructure and business processes that permit interoperability;
- Set standards and policies for data privacy, security and confidentiality of individual records;
- Share information on vital events across programs and sectors ministries through an interoperability layer that links information collected at point of service delivery with data users in multiple systems, including CRVS and the Health Management Information System (HMIS).
- Operational linkages between health information systems across the continuum of care could provide the timely and detailed information needed to generate reliable population data both for programmatic and monitoring uses. Functional links between health information and civil registration across the continuum of care would also contribute to improved notification and registration of births and deaths.
- Maternal and Perinatal Death Surveillance and Response (MDSR) systems can be linked into HMIS and be included in CRVS data as a confidential portion of the birth certificate or death certificate (P14).

Currently efforts are underway to consolidate accumulated experiences on integrated reproductive and pregnancy registries and their potential for interoperability with other health information systems (P13, Figure 6). It would be mutually beneficial to link these to the CRVS

system as is now under consideration in South Africa (P15). Birth and death registration help solve the “denominator question” required for calculating many key development indicators and furnish demographic information such as on the age/gender breakdown of a population that are necessary for planning population health needs, such as immunization and RMNCAH services and commodities. Death registration, with a medically certificated cause of death provides important information on causes of mortality.

Figure 6. Data linkage across the RMNCAH continuum of care (P29)

RMNCAH Care Continuum



A particular case for which the potential mutual benefits for CRVS and RMNCAH systems could be realized is in relation to maternal and perinatal deaths surveillance and response (P14).^{33 34} Where well-functioning civil registration systems exist, the identification of deaths among women of reproductive age provides the starting point for conducting an investigation into the avoidable factors associated with each death. Such investigations often find that in a proportion of cases (up to 20% in some settings), the maternal deaths had been misclassified to non-maternal causes, leading to underestimation of maternal mortality levels.^{35 36 37} These investigations have proved instrumental for identifying insufficiencies in quality of care for pregnant women and their infants.

The Maternal Death Surveillance and Response (MDSR) approach, launched in 2013, is a continuous action cycle linking quality of care improvement with the health system. The core elements of MDSR includes identification and notification of maternal deaths, understanding the causes of deaths and what could be done to prevent future deaths. The recommendations generated from the death reviews need to be acted upon with clear timelines and responsible person and monitored. However, the use of MDSR in countries with weak death registration systems is challenging because notification of the fact of death is poor and pregnancy status is not always flagged in the death certificate. Improvements to Health and CRVS systems to ensure that all deaths are notified by age and sex (even without cause of death initially) would

greatly help in providing the basis for the conduct of maternal death surveillance and response (P14). MDSR in turn could then contribute to more reliable cause of death reporting to the CRVS system.

Reporting systems on fact of death often separate the baby from the mother and there is often no record of stillbirths or early neonatal deaths. As stillbirth and neonatal deaths are often associated with maternal antenatal and delivery this lack of linkage can reduce the ability of the system to understand underlying causes and target programs. Also, where there is no unique identification system in place, it is difficult to link across birth and death registries in order to identify possible missed cases of maternal or infant death. Moreover, tracking of maternal or perinatal deaths is not done in health service areas where the mother-baby pair would be seen e.g. family planning clinics or immunization clinics. This is a missed opportunity for counting all maternal and perinatal deaths. MDSR in turn could then contribute to more reliable cause of death reporting to the CRVS system.

WHO has published a classification system based on the ICD-10 to classify deaths during the perinatal period (ICD-PM) that is applicable across different settings with different diagnostic capabilities (P.14). There are three steps used with the ICD-PM; (i) classify the type of death based on timing (ante/intra partum, stillbirth, neonatal); (ii) identify the main disease or condition that caused the stillbirth or neonatal death; (iii) identify the disease or condition of the mother. With ICD-PM, the perinatal cause of death and the maternal condition are tabulated in a way that highlights the linkages between the two. Furthermore, ICD-PM provides a space to enter the data into the perinatal death certificate with a cause of death (Figure 7).³⁸

Figure 7a. Perinatal death certificate cause of death section³⁸

Causes of death	
(a)	Main disease or condition in fetus or infant
(b)	Other diseases or conditions in fetus or infant
(c)	Main maternal disease or condition affecting fetus or infant
(d)	Other maternal diseases or conditions affecting fetus or infant

Figure 7b. WHO ICD-PM³⁸

Timing of death	Perinatal cause of death	Maternal cause
1. Antepartum	1. Congenital	M1 Maternal complications of pregnancy
2. Intrapartum	2. Antepartum complications	M2 Complications of placenta, cord and membranes
3. Stillbirth (unknown timing)	3. Intrapartum complications	M3 Other complications of labour and delivery
4. Neonatal death	4. Complications of prematurity	M4 Maternal medical and surgical conditions
	5. Infection (tetanus, sepsis, pneumonia, syphilis, diarrhoea)	M5 no maternal conditions identified (healthy mother)
	6. Other cause of death	
	7. Unknown/unspecified	

Both CRVS and RMNCAH systems would greatly benefit from an active surveillance system to identify and notify all maternal and perinatal deaths. This could be facilitated by introducing an electronic system of pregnancy tracking, including longitudinal follow up of maternal and fetal outcomes and building a system of flagging adverse events into the electronic monitoring system (P25). From the CRVS side, an important contribution could involve harnessing the potential of using burial permits to identify deaths in women of reproductive age. Recording of deaths by age and sex would also help in the identification of possible maternal deaths and sharing these with the health sector for investigation.

Strengthening CRVS systems through health facility data

One of the reasons for the low levels of birth and death registration is that traditionally, CRVS systems have relied upon family members to inform the civil registration authorities when a birth or death occurs. When birth occurs in a health facility, the health care worker, midwife or attending physician provides the family with a notification form that includes information about the birth such as sex, date and place of occurrence, and details of the parents. Additional information used for health purposes includes information such as gestational age, birth weight, mode of delivery, any complications and special care. Linking DHIS2 and other HMIS systems with CRVS provides an opportunity for a vital events module to be developed for regularised, standardised data for recording births and death notifications in health systems. (P15, P20, P21)

In the case of a death, the attending physician should provide a medical certificate of cause of death (MCCD) that includes information on the age and sex of the deceased person, the time and place of death, medical cause of death, and other information for administrative purposes such as the decedent's identification number (if available), place of usual residence, and details of the next of kin. This document is often accepted as sufficient to permit the disposal of the body and accompanying rites. The electronic Cause of Death Integrated Reporting System, (eCODIRS) generates consolidated, real-time vital statistics at a national level using the ICD-10 code, whereby the data entered through a Medical Death Certificate and is examined. This not only helps accurate and consistent reporting throughout the system but also ensures standardization, coverage and quality of data.

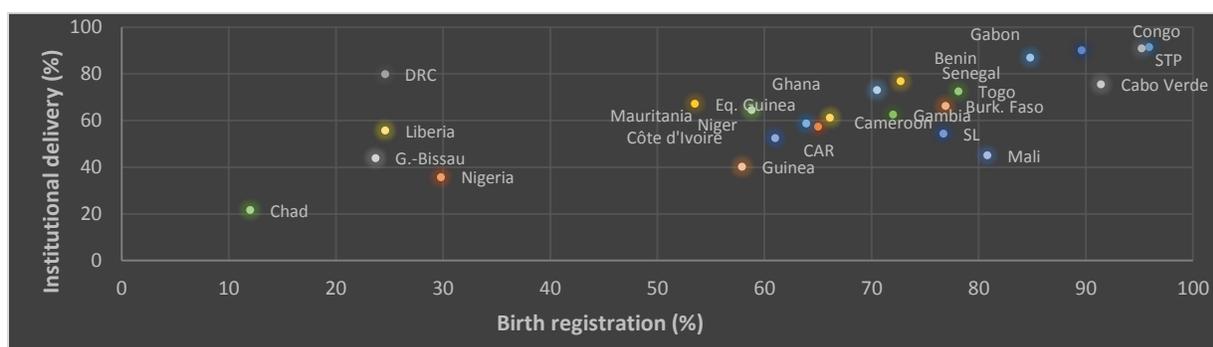
The family is expected to present these notification forms when they visit the civil registrar to register the birth or death, with no further action from the health facility. This is despite the fact that the UN recommends strongly that "facilities of health departments should be employed to assist in registration by notifying the registrar of the occurrence of births, fetal deaths and deaths."³⁹ This more proactive role of health institutions would help to ensure that the registrar immediately receives key information needed for registration purposes; the family would be required mainly to confirm the details such as names, date of birth etc., and to sign the register. This would enable the Registrar to actively follow up where events are not registered, and also to speed up the registration process by independently validating events, and greatly simplify the registration process lessening the burden of responsibility on families.

There is evidence of a relationship between institutional delivery and birth registration (Figure 8). Given that the proportion of births that occur in health facilities is increasing and is very often higher than the proportion of births that are officially registered, this is a potential opportunity to rapidly increase birth registration coverage, as the example of several African countries shows.

Using the health sector in this proactive way as a key agent in the notification of a birth or death has the potential to rapidly increase both notification and official registration and certification of births and deaths and is recommended good practice. However, it places a new responsibility on health care workers across the continuum of care to ensure that they are able to furnish the information required by the civil registrar for legal and administrative purposes. As pointed out

above, this kind of information may not be included in normal health care records. A starting point is to ensure that the minimum data required for a notification of a birth or death is routinely included in the information collected by health workers.⁴⁰ Additional data could be included, however, this must be weighed against ‘responder burden’ – that is, the overburden on health workers, which may risk the integrity of the minimum data collected. It is recommended that countries focus on capturing the minimum necessary data to a high standard.

Figure 8. Opportunities to increase birth registration through health facility notification of births: Example from West and Central Africa¹⁸ (P7)



Sharing responsibilities for birth and death notification between health facilities and families (and for deaths burial authorities) implies the existence of mechanisms to avoid duplicate reporting of the same event, for example by ensuring that critical information is included in the record, such as the ID number of the decedent, name, places of usual residence and identities of the family and declarants.

In addition to its contribution to the notification of births and deaths to the civil registry, the health sector plays a particularly important part in the production of data on causes of death through the completion of the medical certificate of cause of death (MCCD) for all deaths that occur in health facilities with trained physicians. Many countries have interventions designed to enhance the knowledge and skills of medical professionals with regard to cause of death certification. To support this, WHO has a self-teaching module on cause of death certification in the ICD-10 training package which is freely available on the WHO website.⁴¹ The cause of death on the death certificate should be coded by a trained statistical clerk in line with the International Classification of Diseases (ICD) (P21).⁴² Standard application of ICD coding generates statistical categories to a level of detail at 3 or 4 digits. However, in many countries, capacities to classify causes of death at this level are limited. In response, WHO has developed a Start-up Mortality List (SMoL), an automated tool that is in line with the ICD, and informs setting public health priorities and tracking progress towards national and international targets and goals such as the SDGs.⁴³ While the ICD-10 is a useful tool for countries in the early stages of ICD implementation, in the longer term, all countries will wish to proceed to the use of the more detailed ICD listing as their skills and capacities for certification and coding improve.

Potential for collaborative activities

Programs across the continuum of care face challenges in estimating denominators for reliable calculation of rates and ratios, resulting in under- and over-estimation of coverage, inadequate forecasting of commodity needs. They share the need for data on births, deaths and causes of deaths that are:

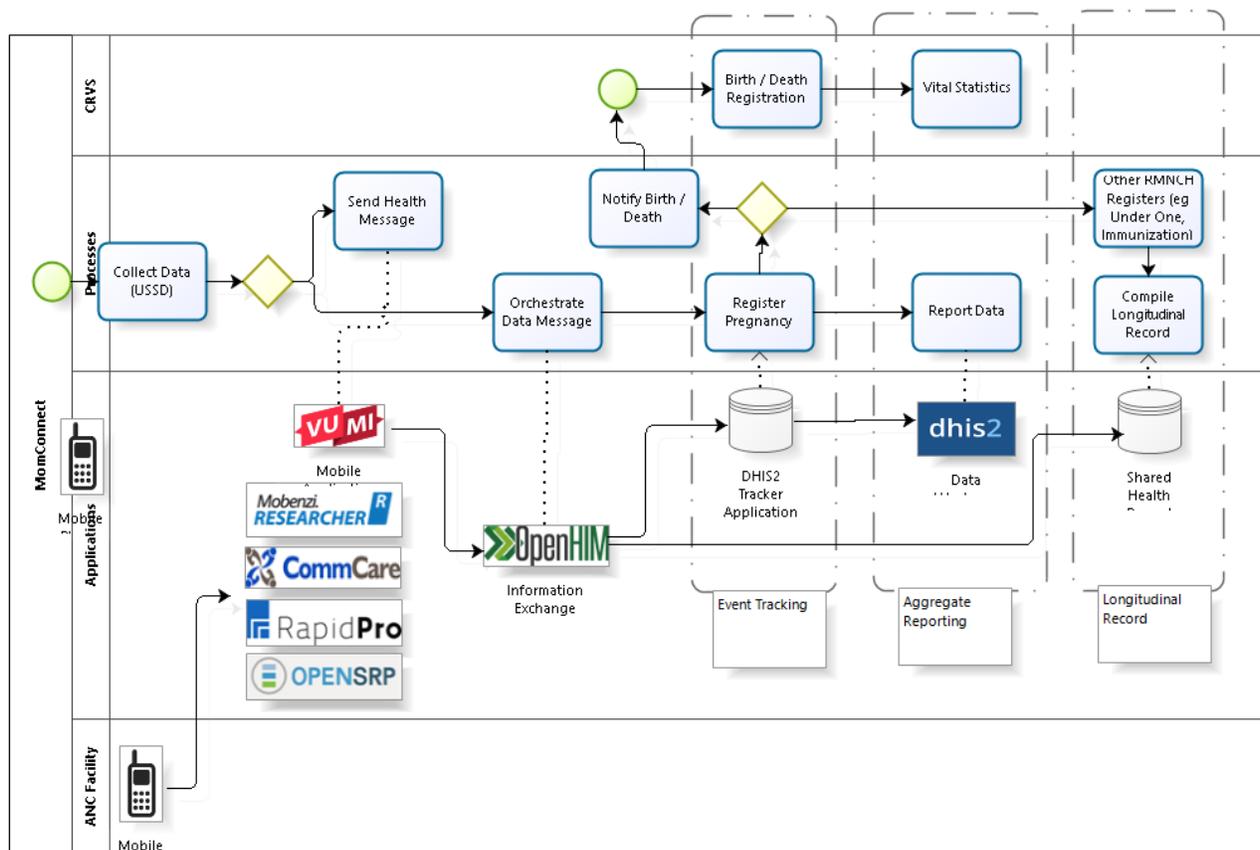
- Complete, universal, timely/real time, detailed, and disaggregated;
- Inform policy decisions, resource allocation, and service delivery; and
- Highlight issues of visibility, vulnerability, exclusion, and inequity.

At the same time, CRVS systems are being challenged to deliver the administrative and legal benefits of registration to individuals and families as well as to improve the availability and quality of vital statistics in order to underpin country policy and planning and facilitate progress monitoring, including of the SDGs.

Meeting participants identified priority areas for collaboration between the health sector and CRVS that could be mutually beneficial both for generating program data across the RMNCAH continuum of care and for strengthening interactions between health and CRVS systems (P6).

Joint assessments and business process mapping: An innovative approach for strengthening CRVS-continuum care interactions is to apply enterprise architecture (EA) and business process mapping (BPM) as part of joint situation assessment and plan development (P15, P24). EA is a tool that applies system science and analysis to better describe, understand, analyze, compare and visualize and organize system processes, workflows and functionality. The approach has been used by the Data for Health Initiative to generate a better understanding of CRVS systems among key stakeholders, including health, registration and statistics sectors, in order to identify bottlenecks, areas where standard procedures are not being followed, and areas of duplication. Involving RMNCAH stakeholders in process mapping would help foster a shared understanding of how to operationalize links between CRVS systems and the continuum of care. A prime example is the extension of pregnancy tracking to the notification of births and deaths to the civil registration authorities, as described in the example from South Africa (Figure 9, P15).

Figure 9. Business process for extending pregnancy tracking to CRVS, South Africa⁴⁴ (P15)



Information and Communications Technology (ICT): Technology has the potential to provide transformative improvements in CRVS systems based on its ability to extend registration coverage, standardize and streamline civil registration and vital statistics processes, integrate data from multiple systems and securely store data at scale, all in a cost-effective way.⁴⁵ If properly employed, ICTs can make a significant contribution towards achieving universal registration of vital events, providing legal documentation of civil registration as necessary to claim identity, civil status and ensuing rights, and producing accurate, complete and timely vital statistics. ICT solutions and technology choices must be appropriate for the country context and based on a thorough analysis of existing systems and infrastructure, eGov policies, CRVS processes, human capacity, financial resources especially for sustainability and operational procedures. RMNCAH data and CRVS systems must be implemented and deployed in a manner, which takes into account the realities of existing health and CRVS sector capacity. Where there is a significant gap between current capabilities and the desired future state, it will be necessary to create an implementation roadmap, such that the scope and timing of change is realistic and manageable. Clear and appropriate governance roles must be established for both RMNCAH and CRVS authorities and IT departments involved in the digitization projects.⁴⁶

The joint development of RMNCAH/CRVS business process maps and the formulation of shared data architecture is a prerequisite for IT introduction and interoperability between health, CRVS and related systems such as unique individual identifiers (IDs). This is a new frontier that potentially can bring huge benefits in terms of data completeness, timeliness and quality through the linking of databases. Unique health IDs are foundational for effective continuity of care and strengthening health information systems and CRVS (P25). Existing ID schemes are often limited to a particular sector or program but they have the potential to support care at multiple points of service, thus connecting disparate care episodes into a longitudinal, person-centric shared health record. This can also increase efficiencies in information flows and reduce the magnitude of the steps in our cascade of care. For example, the OpenHIE Client Registry can be used to support initiatives including CRVS and UHC (Figure 10) (P25). However, it is essential to introduce such initiatives in a context of standards-based governance, data security, and individual privacy. Incorporation of unique IDs into health records and use of data linkage techniques can improve the completeness of birth and death recording and registration and thus generate improved data from RMNCAH program monitoring.

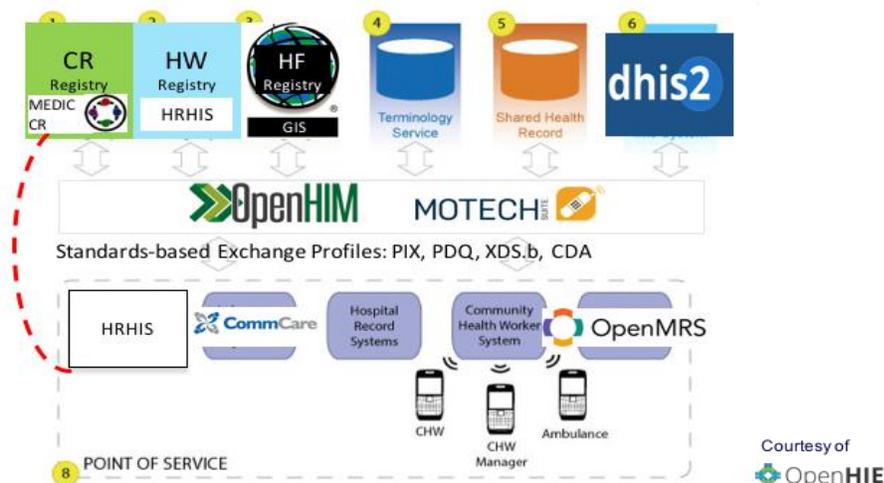
Data collection and management: Data collection instruments need to be re-designed and engineered to incorporate individual data collected for interventions across the continuum of care, and permit aggregations and analyses across geographies and over time. This necessitates the development of common data standards across RMNCAH programs, e.g. register books, tally sheets, individual patient records, home-based records etc. Information collected in the course of RMNCAH program implementation should be made available in the level of detail and with the content required for the registration and certification and births and deaths, including causes of death, as well as for program monitoring purposes. It is essential to forge operational links between CRVS systems and routine health information systems, including for the use of data collection, aggregation, analysis and dissemination tools such as DHIS2 (P20).

Information sharing: The concept of interoperability implies the development of protocols for sharing information and data across health programs and between health programs and CRVS systems and related sectors (ID systems, population register etc.). For this to happen it is imperative to work with communities to address issues of confidentiality, privacy and data security within a sound legal and governance framework. Despite the existence of standards for many aspects of CRVS implementation and for RMNCAH interventions, there is an urgent need to review these and develop guidance in the light of new possibilities presented by IT and the

emerging challenges of monitoring the SDGs, and demands for greater accountability across all sectors.

Figure 10. Health Information Exchange, Myanmar (P25)

Potential Pathway To Interoperable HIS



Capacity development: IT solutions can only be effective where the human resource capacities and skills exist to implement and use them effectively. For this to happen it is necessary to develop and roll out training materials that can be adapted to diverse settings and to set in place institutional mechanisms for capacity development, with a particular focus on RMNCAH and CRVS interoperability. Most low- and middle-income countries need to develop cadres of data stewards and managers empowered to collect, analyze, curate and use data across the continuum of care and in other sectors including vital statistics. Various cadres of workers (social workers, case managers, midwives, CHWs etc.) need to be mandated and trained to work with CRVS systems to increase notifications of births and deaths and ensure that they are officially registered according to international standards. In turn CRVS officials need to assure timely production and sharing of vital data back to national and sub-national planning authorities for health. As part of their support for capacity development, donors and development partners should compile rosters of experts for technical assistance on RMNCAH-CRVS systems strengthening at country, regional, and global levels.

Implementation research: A strong research effort is needed to support evidence-based policy and practice for CRVS in countries and how this could be linked to interventions across the continuum of care. The development of consensus around a CRVS-RMNCAH research agenda is complicated by the fact that there are multiple knowledge gaps, many partners and stakeholders who need to be involved, a complex external environment, and wide diversity of funding sources. There is need for a flexible approach that recognizes the contribution of different players and the mutual benefits that each would derive from closer collaboration in both research and implementation. A first step would be to convene country, regional and global stakeholders to develop a shared priority agenda for research. This would contribute significantly to the development of consensus around priorities and generate significant value add from what would otherwise be a set of unrelated and individual research projects. As part of this, it is essential to bring together lessons learned from country experiences, such as how to facilitate registration among marginalized and vulnerable populations, how to improve the accuracy of cause-of-death data (P27) and ways of scaling up projects designed to introduce ICT and enhance interoperability between Ministries and sectors. Although every setting has its

own particularities and challenges, the findings from implementation research can often be generalized to other settings.⁴⁷

Reaching hard to reach and vulnerable populations

Although by definition civil registration is intended to have universal coverage by virtue of its permanence and compulsory nature, in practice vulnerable and marginalized groups may be excluded due to supply side barriers such as distance to registration sites and discriminatory laws, and demand side factors such as lack of knowledge of the importance of or process for registration, or more value is placed on cultural or religious practices (P30). Those most often excluded from CRVS include displaced, marginalized and hard-to-reach populations, stateless persons, children whose parents were never registered, and people living in informal settlements.⁴⁸ In some settings, women are less likely than men to be registered, as are people with disabilities.⁴⁹ Newborn children are also vulnerable to remaining unregistered at birth and should they die before registration, neither the birth nor the death will have been registered, resulting in significant underestimation of newborn and infant mortality.

Information, encompassing data about who is being left behind and how programs are reaching or failing to reach those in greatest need is a key principle of equitable development. Leaving vulnerable populations out of health and CRVS systems does not only violate the rights of the individual, but also perpetuates intergenerational cycles of poverty and inequality. To address this, improving the availability and quality of data about the most vulnerable populations is critical, including by expanding efforts to measure disparities.

Investing in the most disadvantaged people is not only right in principle, evidence shows⁵⁰ that an equity-focused approach would accelerate progress towards global health goals and would be especially cost-effective in low-income, high-mortality countries. By addressing various forms of inequity in the most disadvantaged populations, it was demonstrated that accelerated progress towards realizing the health goals can be achieved as well as averting more deaths with the same financial investments (P28).

Disparities in maternal, newborn and child health in high-mortality countries represent a major barrier to sustained progress towards every child's right to survive and thrive. Mothers and newborns in the poorest households are also less likely to receive a post-natal check-up. As a result, they are exposed to elevated risks associated with undetected hypothermia, infection and post-birth complications. Women from socially excluded groups often experience hostile treatment or a lack of responsiveness from the health system and health providers (P28).⁵¹

Disparities in the survival and health prospects of children from different backgrounds are not random. They systematically follow the contours of social disadvantage linked not only to wealth but also to ethnicity, education and rural-urban divides, among other factors (P23, P28, P29).

This has a number of implications, including the need to:

- Promote innovative solutions to overcome supply and demand barriers to registration and the generation of vital statistics; including the introduction of new technologies and processes such as signing a MoU between ministries to help reach the hardest to reach.
- Address cultural and discriminatory barriers within laws and policies that prevent vulnerable populations from accessing services.
- Scale up and strengthen the social workforce that helps ensure vulnerable populations have access to the services they need.
- Develop advocacy materials and guidance documents to promote equity and inclusion of vulnerable and hard to reach populations.

The way forward

Recommendations to strengthen CRVS & RMNCAH interactions

At the end of each day the participants met in small groups to have discussions on several thematic areas. After the guided group discussions there would be a report back to the group sharing the group summary of the issues and recommendations.

Arising out of the group discussions at the meeting came a set of recommendations for actions needed to strengthen the collaboration and functional linkages between RMNCAH programs and CRVS systems, to the mutual advantage of both (P29). The recommendations are directed to country CRVS systems, to RMNCAH programs and to development partners and donors (Table 2).

Thematic action areas:

- Policy and governance
- Assessment and planning
- Coordination, partnerships and information sharing
- Innovation, interoperability and IT
- Data collection and analysis
- Technical support and capacity development
- Implementation research
- Advocacy
- Funding

Table 2. Recommendations for strengthening CRVS-RMNCAH interactions

Recommendations for CRVS systems	Recommendations for RMNCAH programs	Recommendations for development partners
Policy and governance		
<p>Establish high level, multi-sectoral coordination committees for CRVS and RMNCAH interactions.</p> <p>Conduct legal and policy reviews and identify strategies to enhance collaboration with RMNCAH programs.</p>	<p>Participate actively in CRVS coordinating committees to ensure that the needs and contributions of RMNCAH programs are taken into account.</p>	<p>Ensure that support to RMNCAH and CRVS country activities is harmonized around a common approach, in line with HDC commitments.</p> <p>Support legal and policy review of barriers to registration of births and deaths.</p>
Assessment, business process mapping, and planning		
<p>Conduct comprehensive assessments of CRVS, involving RMNCAH stakeholders. Revisit roles and responsibilities of different stakeholders.</p>	<p>Participate in CRVS assessments and business process mapping, with a particular focus on birth and death notification, cause of death, and data quality.</p>	<p>Provide financial and technical support for joint CRVS-RMNCAH assessments and business process mapping.</p>
Coordination, partnerships and information sharing		
<p>Facilitate registration of births and deaths through notification of vital events from RMNCAH programs,</p>	<p>Encourage harmonized digital systems for RMNCAH data collection and standards that</p>	<p>Allocate resources for continued updating and management of harmonized health and registration</p>

co-locating registration in health facilities and use of electronic birth and death notifications.	permit sharing of information with CRVS systems, including the notification of births and deaths.	records. Map agencies & partners in CRVS and roles, responsibilities and contributions to CRVS-CoC interactions.
Innovation, interoperability and IT		
Formulate shared data architecture for CRVS-RMNCAH as a prerequisite for IT introduction and interoperability. Document lessons learnt in moving from paper to electronic systems, enhanced interoperability, and mobile registration.	Implement shared IT standards for data collection, data security, and individual privacy across RMNCAH programs and ensure coherence with CRVS standards.	Provide technical and financial support to the development of standards-based open data systems across RMNCAH and CRVS systems.
Data collections and analysis		
Establish appropriate governance roles for CRVS, IT departments, ID systems and interested stakeholders including RMNCAH. Conduct regular analyses of completeness of birth and death registration, with particular focus on marginalized groups. Establish linkages between unique IDs and CRVS and support data linkage techniques to improve the completeness of birth and death recording and registration.	Ensure that records across the CoC satisfy CRVS standards for births and deaths, including information required for legal, administrative and statistical purposes. Incorporate unique IDs into health records and use of data linkage techniques to improve the completeness of birth and death recording and registration.	Support the development of innovative methods for estimating population denominators and birth and death registration coverage at national and subnational/local levels and methods for calculating rates and ratios. Conduct comparative reviews of country experiences and lessons learnt in linking CRVS to health data systems, with a focus on the continuum of care.
Technical support and capacity development		
Develop activities to enhance technical capacities of CRVS across the continuum from notification, to registration, certification and production of vital statistics.	Specify the central role of RMNCAH personnel and their potential for greater involvement in registration. Provide training and awareness arising to relevant health personnel.	Compile rosters of technical expertise, consultants and technical staff for deployment to countries.
Implementation research		
Document utility of and lessons learnt from business process mapping for CRVS and RMNCH at national and subnational levels. Identify and evaluate demand-side incentives for birth and death registration, e.g. eligibility for benefits, access to subsidized services.	Map CRVS/MNCH interaction points, global/regional status of interoperability, interventions, donor support, and implementing partners, by region. Assess roles of community health workers and other community level personnel in improving utilization of continuum of care and ensuring registration of vital events.	Evaluate strategies for reaching vulnerable populations and overcoming cultural, legal and policy barriers to use of health services and registration of births and deaths. Evaluate the potential role of satellite mapping and other innovations for identifying underserved areas and populations for RMNCH-CRVS.

<p>Identify and address supply side efficiencies for increasing registration & certification, e.g. electronic signatures of certificates, batch transfer of certificates from registration offices to local health facilities or local authorities.</p> <p>Develop strategies for reaching vulnerable populations and overcoming cultural, legal and policy barriers to CRVS.</p>	<p>Study ways of using unique IDs in health records to track defaulters from immunization and follow up to check on survival and notification and registration.</p> <p>Assess role of RMNCAH programs in reaching vulnerable and marginalized populations and promoting birth and death registration.</p>	<p>Support testing of new survey questions to better measure registration completeness and coverage of continuum of care interventions at national and subnational levels.</p> <p>Conduct technical reviews of digital tools and checklists against criteria such as comparative advantages in information analyses, business models, and associated functional interoperability over the short, medium and long term.</p>
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Advocacy

<p>Advocate to CRVS stakeholders the potential contribution of RMNCAH programs to CRVS systems, in particular for the registration of births and deaths and information sharing on causes of death.</p>	<p>Advocate for CRVS messaging to be integrated into existing advocacy platforms such as EWEC, ENAP and major events (WHA, UNGA, World Humanitarian Day, Day of the Girl Child etc.).</p>	<p>Develop advocacy brochures, policy briefs, working papers and academic publications on best practices and current state of interoperability across CRVS, health, RMNCAH in context of SDG agenda</p> <p>Issue joint statements at highest level agreed between partners within health, CRVS, ID systems, community organizations and other stakeholders. Incorporate into EWEC advocacy and communication strategies</p>
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Funding

<p>Explore innovative funding mechanisms to address the multi-sector and multi-faceted challenges to CRVS and RMNCAH Continuum of Care linkages.</p> <p>Provide technical and financial support for CRVS assessments, multi-sectoral stakeholder analyses and business process mapping to link RMNCAH Continuum of Care and CRVS.</p> <p>Support the development of communication and advocacy materials, including documenting good practices in overcoming supply and demand barriers to registration from country experiences and formulate guidance based on lessons learned.</p> <p>Scale up the technical expertise around CRVS through capacity building activities such as administering trainings and workshops and creating a roster of experts to be deployed for technical guidance and support.</p> <p>Convene demonstration countries to inform the development of guidance for the shift from paper-based to digital CRVS and RMNCAH continuum of care data systems.</p> <p>Funding to strengthen partnerships and collaboration between the multi-sector stakeholders around CRVS and develop guidance on cross-sectoral integration and programming.</p>

Conclusion

The multiple threats to the survival and well-being of the most vulnerable women and children are not divided by sector. Harnessing opportunities to link CRVS and health systems and ensure interoperability would greatly improve the availability and quality of vital statistics. Linking data across other sectors and systems such as education and social welfare, provide valuable opportunities to generate better information and lead to a more in-depth understanding of the multiple deprivations that may deny women and children a fair chance in life.

There is no substitute for fully functioning CRVS systems. Birth and death data, combined with information on migration, hard to reach and vulnerable populations who may be missed by both surveys and CRVS systems, enable the production of accurate population estimates – the denominators for compiling most indicators – at national and subnational levels. Data generated by CRVS systems can be used to benefit the most disadvantaged and hardest to reach people, but only if it is truly universal so that no woman or child is left behind or goes uncounted.⁵²

An important aspect of building CRVS systems is ensuring that information on births and deaths is submitted to the civil registry as soon as possible following occurrence so as to maximize the reliability and completeness of the information reported. The ‘Continuum of Care’ – defined as integrated services for mothers and children from pre-pregnancy to delivery, the immediate postnatal period, and childhood – offers a key mechanism for birth and death notification and registration. Data collected during the provision of antenatal care, delivery, postpartum care, immunization and maternal, newborn and child health services are used both to strengthen RMNCAH programs and also generate information on birth and deaths needed and for the effective functioning of the CRVS system.

The realization of the mutual benefits between health and CRVS systems requires that programs across the continuum of care should have the ability to identify vital events, record key characteristics required by the CRVS and health information systems, and notify the civil registry accordingly, preferably by electronic means so as to minimize data transmission errors. For this to occur, the content of health records for infants, children, adolescents and women of reproductive age must include the core information items required by the civil registry. Better integration of health care and registration functions implies some systemic changes to the ways in which both health information and registration systems function, including:

- Shared data standards across the interventions along the RMNCAH continuum;
- Address legal and policy barriers to registration such as gender and cultural barriers
- Linking individual records over time and across interventions, preferably through a unique ID;
- Data architecture and business processes that permit interoperability;
- Possible co-siting of registration points within health facilities;
- Standards for data privacy, security and confidentiality of individual records;
- Sharing information on vital events across sectors.

Coordination between ministries of health, civil registration authorities and the national statistics office, through an inter-agency, cross-sectoral committee, is essential. Technological innovations can be used to increase birth registration by overcoming barriers such as distance to registration points and through integrating CRVS systems with existing health databases. Strengthened health sector and CRVS system interactions, whereby the health system infrastructure captures information about births and deaths, thus strengthening the CRVS system. In turn, the statistics and information generated by CRVS are used to inform health policy and planning across the continuum of care.

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