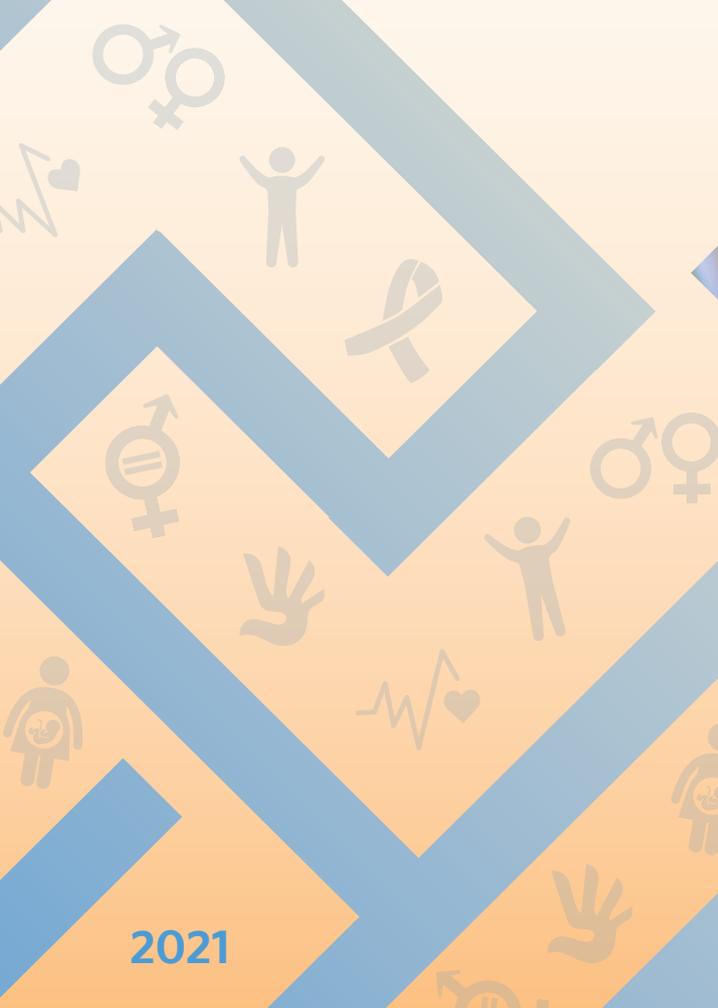


# Improving data for evidence-based decision-making:

Reinforcing **civil registration and vital statistics** and **maternal and perinatal death surveillance and response** systems interlinkages

Guidance note for development and humanitarian settings



# CONTENTS

Acknowledgement	4
Disclaimer	4
Acronyms and abbreviations	5
Glossary	6
Background	8
The need for effective mortality surveillance systems	8
Civil registration and vital statistics (CRVS) systems	10
Maternal and perinatal death surveillance and response (MPDSR) systems	11
Critical gaps and challenges in CRVS and MPDSR systems and the need for integration	15
Guidance on integrating data from CRVS and MPDSR systems in development and humanitarian settings	19
Who is this guidance note for?	19
What is the objective of this guidance note?	19
How should this guidance note be used?	19
Stage one – preparation	24
Stage two – analysis and design	52
Stage three – implementation planning	61
Next steps and recommendations	70
Annex 1. CRVS/MPDSR data integration planning template	73
Annex 2. Business case template	82
Reference list	85

# Acknowledgements

This guidance note was commissioned by the UNFPA Arab States Regional Office (ASRO) Population and Development team in coordination with the Sexual and Reproductive Health team. Funding was provided by the Canadian International Development Research Centre, Centre of Excellence for Civil Registration and Vital Statistics Systems.

The guidance note was developed by Nicola Richards, independent consultant. Renee Sorchik, Technical Specialist – Population and Humanitarian Data, UNFPA ASRO, edited the report and provided overall guidance.

UNFPA acknowledges the efforts of those who contributed in the production of this report. Special thanks go to the following experts for their review: Shible Sahbani - Regional Advisor, Reproductive Health, UNFPA ASRO; Mohamed Afifi – Technical Specialist, UNFPA ASRO; Eman Aly, WHO EMRO; Azza Badr, WHO Geneva; Chokri Benyahia – Programme Specialist, UNFPA ASRO; Daniel Cobos, Swiss Tropical Health Institute; Nada Gaafar – Expert, Sudan; Rhode Janssen - Sexual and Reproductive Health Analyst, UNFPA ASRO; Eduard Jongstra – Population Advisor, UNFPA EECARO; Ismail Lubbad – UNESCWA; Njah Mansour – Expert, Tunisia; Nilmini Nilangani, WHO EMRO; Awad Shboul – Expert, Jordan; Romesh Silva – Population Development Branch, UNFPA; Hala Youssef - Population and Development Advisor, UNFPA ASRO.

Special thanks go to UNFPA Arab States Country Offices for their support in providing relevant materials, documents and review.

## Disclaimer

This document has been produced with the financial support from UNFPA. The views expressed herein can in no way be taken to reflect the official opinion of the United Nations, including UNFPA, or the UN member states.

# Acronyms and abbreviations

<b>ASRO</b>	Arab States Regional Office, UNFPA
<b>CEMD</b>	confidential enquiry into maternal deaths
<b>CRVS</b>	civil registration and vital statistics
<b>HIS</b>	health information system
<b>HMIS</b>	health management information system
<b>ICD</b>	International Classification of Diseases and Related Health Problems
<b>IDPs</b>	internally displaced persons
<b>MDR</b>	maternal death review
<b>MDSR</b>	maternal death surveillance and response
<b>MMR</b>	maternal mortality ratio
<b>MPDSR</b>	maternal and perinatal death surveillance and response
<b>NMR</b>	neonatal mortality rate
<b>PNMR</b>	perinatal mortality rate
<b>UN</b>	United Nations
<b>UNFPA</b>	United Nations Population Fund
<b>UNHCR</b>	United Nations High Commissioner for Refugees
<b>VA</b>	verbal autopsy
<b>WHO</b>	World Health Organization

# Glossary

## Data integration

Data integration is the combination of technical and business processes used to combine data from disparate sources into meaningful and valuable information. Data integration can include combining data from multiple sources; combining geospatial data with other data; data pooling; unit-record data linkage; data fusion; and data prioritization, when two or more sources contain data for the same variable, with potentially different values (1).

## Data validation

A method for checking the accuracy and quality of data before further processing. Data validation techniques include checking for completeness (no blank or null values), checking for uniqueness (values are distinct and not duplicates), and checking if the range of values are consistent with expected patterns (2).

## Humanitarian setting

Humanitarian settings, those arising from natural disasters, armed conflict, a public health emergency or other hazards, are broadly defined as emergency situations with large-scale injury and death, insecurity, a sudden or large influx of people, malnutrition, disease, and disrupted economic, political, health, and social institutions (3).

## Maternal death

The death of a woman while pregnant or within 42 days of the termination of pregnancy irrespective of the duration and site of the pregnancy, from any cause related to or aggravated by the pregnancy or its management but not from accidental or incidental causes. Maternal deaths can be divided into:

**Direct obstetric deaths** are maternal deaths resulting from obstetric complications of the pregnancy state (pregnancy, labour, or puerperium); from interventions, omissions, or incorrect treatment; or from a chain of events resulting from any of the above.

**Indirect obstetric deaths** are maternal deaths resulting from previously existing disease or disease that developed during pregnancy. These deaths are not due to direct obstetric causes, but are aggravated by the physiological effects of pregnancy (4).

- Mortality audit** A mortality audit is the process of capturing information on the number and causes of maternal and perinatal deaths, and then identifying specific cases for systematic, critical analysis of the quality of care received, in a no-blame, interdisciplinary setting, with a view to improving the care provided to all mothers and babies. It is an established mechanism to examine the circumstances surrounding each death including any breakdowns in care that may have been preventable (5)
- Perinatal death** Stillbirths and early neonatal deaths (deaths among live-born children up to 7 completed days of life) (6).
- Neonatal death** The death of a live birth during the first 28 completed days of life. Neonatal deaths may be subdivided into early neonatal deaths, occurring during the first 7 days of life, and late neonatal deaths, occurring after the 7th day but before the 28th completed day of life (6).
- Stillbirth** Third-trimester stillbirths – at 1000g birth weight, 28 completed weeks of gestation and 35 cm body length, with birth weight given priority over gestational age (6).
- Underlying cause of death** (a) The disease or injury which initiated the train of morbid events leading directly to death, or (b) the circumstances of the accident or violence which produced the fatal injury (7).
- Unit-record data linkage** The process of identifying and linking records at the individual (unit) level, which belong to the same person, so that records found in one system but not the other can be used for validation of data quality for both systems, and/or included in some form in both systems to improve coverage and thus data quality (1, 2).

*Also referred to as 'record linkage'.*

# Background

## The need for effective mortality surveillance systems

Maternal mortality remains unacceptably high: globally, each day approximately 810 women die from preventable causes related to pregnancy and childbirth (6). Further, of the estimated 6.2 million deaths among children less than 15 years old each year, 2.5 million of these occur among newborns – some 6,800 deaths per day; the majority of which are also preventable through the provision of quality care during pregnancy, delivery, and the first 28 days of life (7). The Arab region has the third highest regional maternal mortality ratio in the world at 151 maternal deaths per 100,000 live births (8). Despite the importance of information on health seeking behaviours and health services accessed for pregnant women and mothers, and health outcomes for women and newborns during pregnancy, labour, delivery and the first 24 hours post-partum (9, 10), there are few examples of success in effective health surveillance and monitoring systems in resource-poor settings, with efforts often falling short of having a tangible impact (11).

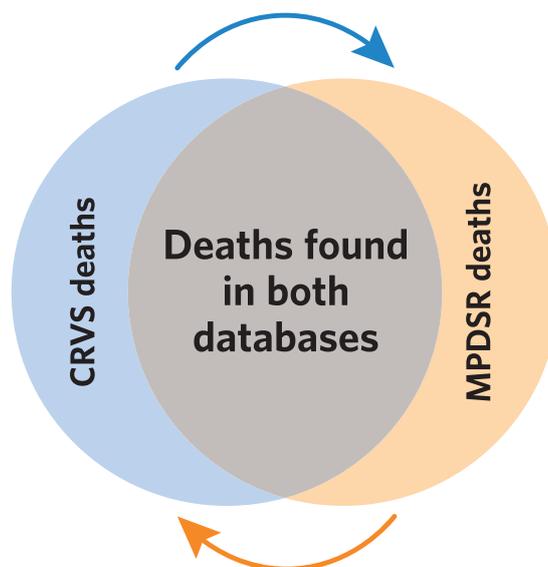
Maternal and perinatal death surveillance and response (MPDSR) systems refer to the notification, review, analysis and response to maternal and perinatal deaths, and are a form of continuous surveillance linking health information systems (HIS) and quality of care improvement processes from local to national levels. They were developed to help avoid preventable maternal and perinatal mortality and morbidity through the identification of critical failures in the care pathway and taking action to prevent similar deaths occurring in future. MPDSR draws on the health management information system (HMIS) of a country and can be strengthened through integration with the civil registration and vital statistics (CRVS) system.

Many maternal and perinatal deaths go unrecorded or are misclassified because the system for CRVS is weak. Accurate maternal and newborn mortality rates require robust CRVS systems that record every death and cause of death correctly. Accurate and comprehensive information about the causes of women's deaths can be difficult to acquire and therefore difficult to label as maternal deaths. The scale of the problem, including under-notification among other issues, was reported in the recent maternal death surveillance and response (MDSR) analysis conducted by the United Nations Population Fund, Arab States Regional Office (UNFPA ASRO) (12), and was also indicated by confidential enquiries into maternal deaths in some countries (13, 14), where

more maternal deaths were identified as part of the MDSR system than those notified or registered in the local CRVS system.

An effective MPDSR system informs on the main causes of maternal and perinatal deaths and produces accurate and complete estimates of maternal and perinatal mortality, providing robust and consistent data for monitoring trends in mortality and related medical and systemic causes of death. Where reliable CRVS systems do not exist, MPDSR can provide a cornerstone of a new system, and contribute significantly to a country's 'culture of accountability' and evidence-based decision and policy making by connecting actions with results to put in place interventions that support a woman's right to life and safe childbirth, and a child's right to life.

There is a need for the two systems to be mutually reinforcing (Figure 1). If well integrated, MPDSR can help strengthen the CRVS system by providing a more holistic picture of mortality, particularly when more deaths are captured in the MPDSR system than officially registered with civil registration. Deaths found in the CRVS system but not in MPDSR allow for identifying gaps and for a more complete register of deaths during pregnancy, delivery, abortion or the post-partum periods, which can then be investigated by cause. This creates a more comprehensive assessment of the extent of maternal and perinatal deaths and a better understanding of the causes of death, allowing policymakers to respond, supporting pregnant women at increased risk and creating more effective interventions to prevent maternal and perinatal deaths. It also helps to improve the quality of care and measure quality of care improvements. Improvements to HMIS 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 and perinatal death reviews, and ultimately establishing MPDSR systems. MPDSR in turn could then contribute to more complete reporting of deaths and reliable cause of death reporting to the CRVS system.

**Figure 1:** Making mutually reinforcing CRVS and MPDSR systems

Source: Author's own

## Civil registration and vital statistics (CRVS) systems

A civil registration system, as defined by the United Nations' Principles and Recommendations for a Vital Statistics System (7), is the:

*"...continuous, permanent, compulsory and universal recording of the occurrence and characteristics of vital events pertaining to the population, as provided through decree or regulation in accordance with the legal requirements in each country (paragraph 279, page 65)."*

Vital events including births, deaths, marriages and divorces are translated into statistics through a country's vital statistics system (7). A CRVS system, in turn, refers to the production, dissemination and use of statistics on vital events as captured through civil registration. At an individual level, civil registration provides essential legal documentation for many purposes; while the generated record of births, deaths and causes of death also provides critical and crucial evidence on population health (9). CRVS systems are often referred to as the foundation of a country's health system, providing information on trends in fertility and mortality to allow for effective decision making and resource allocation (10). The recording of live births and deaths by age – basic functions of any civil registration system – allows for the identification of potential maternal and perinatal deaths, and the generation of key indicators such as the maternal mortality ratio (MMR), perinatal mortality rate (PNMR) and neonatal mortality rate (NMR).

Vital statistics derived from CRVS systems are the best source of nationally representative and continuously available information on cause-specific mortality; of critical importance in understanding trends in causes of maternal and perinatal deaths (9). Accurate statistics on causes of death are supported by a well-functioning CRVS system that uses the International Form of Medical Certificate of Cause of Death for medical certification, and codes according to the International Classification of Diseases (ICD); particularly important in ensuring that deaths related to indirect maternal causes and pregnancy are not 'missed' in the system. Given their continuous nature, CRVS systems are also able to provide data over extended periods of time, allowing for countries to monitor trends in key indicators such as the MMR and NMR, and to assess the impact of national policies and programs aimed at improving maternal and newborn health.

As well as providing important demographic statistics, recording of vital events is a human rights issue (11). Through the process of birth registration, the State recognises a person before the law; while through death registration the State can legally end a person's civil status and 'retire' his/her legal identity (15). Well-functioning CRVS systems also have disproportionately positive benefits for women and girls, along with refugees and internally displaced persons (IDPs) (16). Civil registration ensures that children are provided with legal identity from birth, allowing them access to crucial public services such as health and education.

## **Maternal and perinatal death surveillance and response (MPDSR) systems**

Acknowledging the growing demand for more accurate and comparable data on maternal and child mortality, the World Health Organization (WHO) had introduced specialised verbal autopsy (VA) tools in the 1990s to systematically record information on causes of death (10). However, it was their landmark 2004 publication, *Beyond the Numbers* (17), that encouraged all countries to establish systems of maternal death surveillance and response (MDSR). More recently, critical publications such as *Making Every Baby Count* (6), have provided countries with guidance on implementing systems for monitoring stillbirths and neonatal deaths. Collectively, MPDSR systems collect accurate information on how, where and why many maternal and perinatal deaths occurs, and what can be done differently to prevent future (similar) deaths. They are a continuous audit and action cycle linking HMIS with quality improvement cycles (6, 18): aggregating and linking information with the aim

of developing and implementing coordinated local and national responses to eliminate preventable maternal and perinatal mortality (19).

MPDSR systems include the routine and continuous identification, notification, quantification and determination of the causes and avoidability of maternal and perinatal deaths, providing information that effectively guides immediate and long-term actions and counts every death (4, 20). Mortality audit and feedback cycles have been shown to have a greater impact on health care practices than other quality improvement strategies, and when expanded to include surveillance (the systematic collection and analysis of all deaths at every level), have the ability to use data and peer review to improve the quality of care and reduce preventable deaths (21). Through the inclusion of VA and social autopsy (SA),<sup>1</sup> MPDSR systems provide detailed, rich information on the pathways leading to death, along with highlighting potential areas for improvement (10).

### There are six main steps in MPDSR systems (Figure 2) (6):

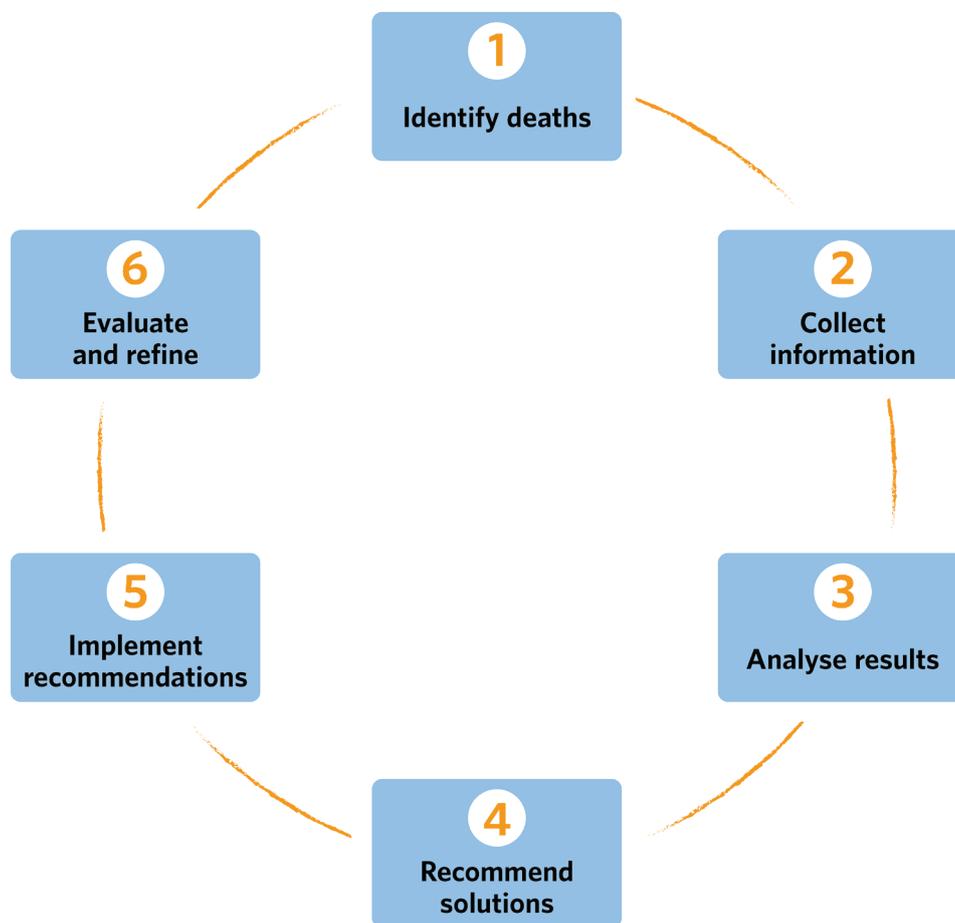
1. **Identification of deaths.** Various records and registers from health facilities may be used during this step, including case notes and death registers from labour and delivery, postnatal, and general adult inpatient and outpatient wards (22). The identification of deaths in the community is a critical component of any effective MPDSR system (23), along with one of the major challenges, given the number of various stakeholders involved.
2. **Information collection.** Important decisions around what data to record, where and how to record and store it, and by whom, all need to be clearly defined during this step, with data quality a major problem affecting MPDSR implementation.
3. **Analysis of results.** During this step, the cause of death and modifiable factors are assessed and discussed during routine meetings.
4. **Recommend solutions.** The development of action plans with clear processes for monitoring follow-up on action items is a critical component of this step. The formation of appropriate recommendations based on results can be challenging, especially when many of the proposed solutions are outside of the immediate control of the health system.
5. **Implementation of recommendations.** The inclusion of various health care workers is important in this step – from clinical staff to

1. Focussed on the social and health system determinants of mortality, including care processes and pathways, and the barriers in seeking, reaching, and receiving care.

information and quality improvement officers, lab technicians and pharmacists. Focussing on recommendations within the control of health care workers often results in effective implementation, while a lack of community engagement can act as a significant barrier to implementing actions outside of the health care sector.

6. **Evaluation and refinement.** This final step is focussed on looking at what worked in the system, and what did not – providing an opportunity for reflection and improvement.

**Figure 2:** Six-step cycle for MPDSR systems



**Source:** Adapted from Sunguya et al, 2018 (22)

A key enabling factor of any MPDSR system is accountability – in terms of both individual and collective answerability and enforceability (24). Assigning a district maternal and perinatal death review coordinator, who receives data from focal points at the facility and community level, is also critical to the overall process and in driving the required ‘culture of accountability’ (24). There are also more basic resources required, such as ensuring enough stationary to complete review paperwork and the development of standard

operating procedures (SOPs). In analysing maternal death reviews from over 60 years and in many contexts, authors identified three critical enabling factors of success (18):

1. Individual responsibility and ownership.
2. A proactive institutional ethos that promotes a learning culture as a crucial part of improving services and the quality of care provided.
3. A supportive political and policy environment at the national and local level.

# Critical gaps and challenges in CRVS and MPDSR systems and the need for integration

While CRVS systems contribute to the effective monitoring of, and accountability for maternal and perinatal deaths, not all systems include cause of death as part of death registration, and none routinely includes information on factors that led or contributed to death – making it difficult to ensure all maternal deaths are accurately identified as such (11). The identification of maternal deaths also depends on the accurate identification of women who were pregnant or within 42 days of termination of a pregnancy at death. This is challenging as pregnancy status is not consistently included in death certificates, abortion-related deaths are particularly difficult to identify, and while some causes of death are automatically linked with maternal deaths, others are not (11). Overall, maternal and perinatal mortality remain difficult to measure, with many CRVS systems affected by low coverage and high rates of underreporting (25).

Despite their clear benefits, critical gaps and challenges also persist among MPDSR systems. These include the large amount of missing data, poor documentation and quality of case notes (22), overall staff shortages, difficulties in obtaining data on community factors leading to death, the large amount of information generated through reviews (which can be difficult to interpret), and a fear of blame and punishment over deaths (26). For maternal deaths, two major challenges are, firstly, identifying adult female deaths, and secondly, determining if deaths are maternal or pregnancy related (27). Further, the inclusion of perinatal deaths in MPDSR systems is very low, with the accuracy of recording such deaths a serious issue – not all cases may be recorded in health facility registries due to differences in definitions on stillbirths and intrauterine deaths, cultural practices in delaying birth registration to avoid the need for a death certificate if a newborn does not survive, and higher normative acceptance of such deaths (12, 28, 29). It is very difficult to include all perinatal deaths in any system of MPDSR given their much higher numbers, limited opportunities for recording the factors leading to death, and a lack of community engagement and participation in the process (11). Perinatal deaths are also unlikely to be included in any national policy that set stillbirths and neonatal deaths as notifiable at the national level (6).

Given these critical gaps and challenges, strengthening data integration between CRVS and MPDSR systems has the potential to improve both. When neither system have full population coverage or low completeness, cross-checking and validating the data stored in each can substantially improve the quality of data on maternal and perinatal mortality for the country and coverage of MPDSR and CRVS systems, respectively. Given that, for maternal and perinatal deaths, CRVS and MPDSR systems are monitoring the same vital events among the same populations and in the same country – it also makes sense that the systems are collaborating and working synergistically (30). MPDSR systems contain a volume of existing, high-quality data on maternal and perinatal mortality that could and should be integrated with civil registration data and used in national health planning (**Box 1**). While MPDSR systems cannot substitute for universal civil registration, their implementation can provide supplemental vital statistics on maternal and perinatal mortality until CRVS systems of sufficient quality and completeness are established, and until representative cause of death statistics can be reliably produced (30).

### **Box 1. Integrating CRVS and MPDSR data in Nigeria**

In Nigeria, national guidelines ensure that “...data generated from the MPDSR processes be directly linked, at all levels, to the existing HMIS...,” and, “...the ultimate means to capture information on all deaths, including maternal and perinatal deaths, is the CRVS [system]...This MPDSR process can contribute to a resurgent CRVS system in the country”.

**Source:** *adapted from Shittu & Kinney, 2017 (31)*

## **Data integration**

Data integration, broadly **defined as the variety of technical and business processes used to combine data from disparate sources into meaningful and valuable information** – creates rich datasets that are useful in assessing service use and outcomes, and for comparing the accuracy of data across sources (1, 2). Data integration can include:

- Combining data from multiple sources, as part of the creation of integrated statistics.
- Combining geospatial data and statistical data or other non-statistical data.
- Data pooling, with the aim of increasing the effective number of observations of some phenomena.
- Matching or unit-record linkage, with the objective to link micro or macro data from different sources.

- Data fusion – integration followed by reduction or replacement.
- Prioritizing, when two or more sources contain data for the same variable, with potentially different values (1).

Unit-record data linkage, commonly used in health care evaluation, enables researchers to measure care across sectors, assess the integration of care, consider long-term patient outcomes, monitor service provision, identify adverse outcomes, and compare data obtained from different sectors or agencies (32). For maternal and child health, unit-record linkage can provide valuable information on maternal morbidity prior to birth and maternal risk-factors for adverse birth outcomes (**Box 2**) (33). Data linkage can also highlight systematic biases in certain data sources – such as civil registration systems. A data linkage study in South Africa, for example, was able to match 61% of deaths recorded in a local Health and Demographic Surveillance System (HDSS) to those registered with the CRVS system, indicating a minimum level of registration completeness (34). Importantly though, the study demonstrated significantly lower levels of matching for deaths of children less than five years old (38%), indicating their deaths were less likely to be registered within the CRVS system.

### **Box 2. Country case study: linking maternal mortality data in Australia**

While Australia has comparatively low levels of maternal mortality, with advances in medical technology keeping patients alive for longer periods; women who may have died during pregnancy or within six weeks of birth are dying later. Research conducted by State and Territory Maternal Mortality Committees indicated that many of such deaths were being missed by existing surveillance systems due to inefficient processes to identify late maternal deaths, and limited agreement on the value of investigating or reporting late deaths.

As such, the Australian Maternal Mortality Project was established to develop a nationally consistent and confidential maternal death enquiry system and an enhanced process for the ascertainment of late maternal deaths (deaths later than six weeks but less than one year after pregnancy). Data linkage was seen as a particularly valuable process as it is population based, uses routinely available data, and has the potential to be a sustainable surveillance tool for maternal deaths. An extract of deaths collected in one jurisdiction in Australia was linked to national-level death data for the period 1994–2002. The linkage identified 173 maternal deaths: 97 maternal and 76 late maternal deaths.

**The linkage identified 19 new maternal deaths (occurring <42 days after birth) that were not known to the jurisdiction, representing a 20% increase in ascertainment for the study period.** The 76 late maternal deaths included three direct and 73 indirect maternal deaths. Only six (8%) of the late maternal deaths were known to the jurisdiction's Maternal Mortality Committee. The most common causes of late maternal deaths were: suicide, cardiac disorders, accidents and violence. Further, late maternal deaths were as prevalent as maternal deaths in pregnancy and the puerperium, indicating that the true maternal mortality ratio in Australia could be significantly higher than reported.

**Source:** Adapted from 'Maternal mortality: Data linkage methodology,' available at:

<https://www.aihw.gov.au/getmedia/751e7c22-a653-4376-b6f6-8003768617a1/17992-per65.pdf.aspx?inline=true>

# Guidance on integrating data from CRVS and MPDSR systems in development and humanitarian settings

## Who is this guidance note for?

This guidance note was developed for UNFPA ASRO Country Office staff to use during discussions with national counterparts on the design and implementation of activities developed to strengthen data integration between CRVS and MPDSR systems. It is envisioned that staff will use the guidance note as a practical tool to assist during the planning and implementation stages, by offering a structured approach to follow and a consolidated summary of key resources on the topic, including where to go to find more information.

## What is the objective of this guidance note?

The objective of this guidance note is to make data more robust, thus improving its usability for policy purposes. By making CRVS and MPDSR systems mutually reinforcing, the coverage of events is greater, which improves data quality and can lead to more complete mortality data for the CRVS system to generate mortality indicators and to target population groups where registration is low, and a larger base of deaths of neonates and women of reproductive age to investigate and better understand causes of death, resulting in better health interventions.

## How should this guidance note be used?

This section provides practical guidance for assessing if the basic requirements for effectively integrating data from CRVS and MPDSR systems are in place. For the purpose of this guidance note, data integration is defined as the **variety of technical and business processes used to combine data from disparate sources into meaningful and valuable information for assessing service**

## **use and outcomes, and for comparing the accuracy of data across sources.**

Guidance is provided for three types of data integration, namely simple cross-checking of aggregate data tallies, the validation of aggregated data and unit-record data linkage. More information about each of these options is outlined in section 1F.

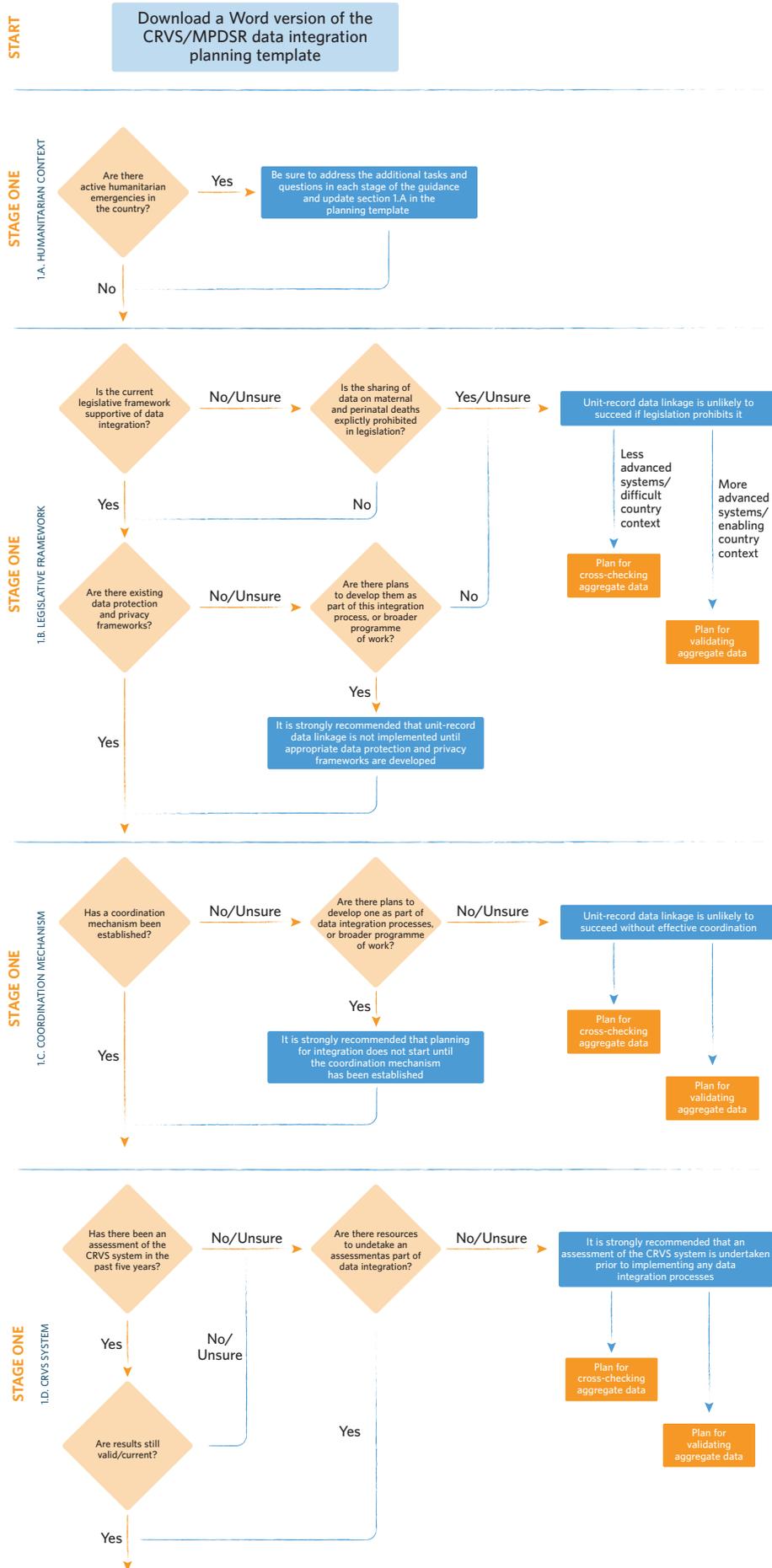
To use this guidance – UNFPA Country Office staff, in cooperation with government agencies involved in CRVS and MPDSR, and other partners, are recommended to work through a series of questions and tasks that have been divided into three stages. These stages are summarised in the flowchart below and explained in more detail on the following pages:

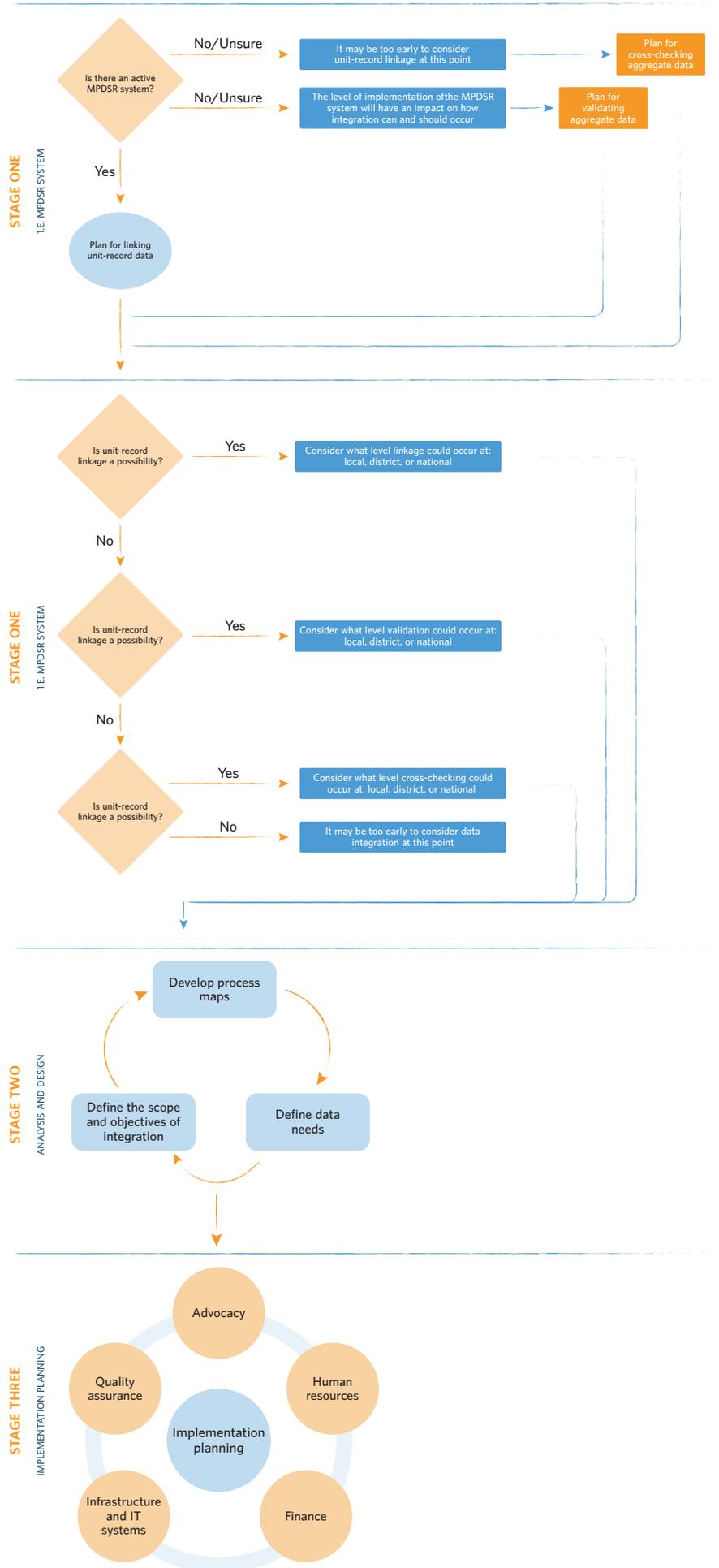
- **Stage one – preparation.** Considers any existing humanitarian emergencies in the country, along with an assessment of existing legal frameworks, coordination mechanisms, and robustness of the CRVS and MPDSR systems. A series of questions are presented for consideration as part of the preparation stage. **For countries with active humanitarian emergencies, additional tasks and questions should be considered at each stage**, which are highlighted throughout the document (**green text boxes**). In countries that do not have active humanitarian emergencies, users do not need to read the green text boxes or complete the additional tasks and questions. While each question could be dealt with in any order, the order presented offers a logical way of working through them against the information being collated in Annex 1 (which will be updated as users work through the guidance). At the end of stage one, users should have determined what kind of integration may be possible, namely:
  1. **Cross-checking aggregate data.** Performing a basic comparison of the number of maternal and perinatal deaths registered by civil registration to those recorded in the MPDSR system to assess potential under-counting in either system.
  2. **Validating aggregate data.** Checking the accuracy and quality of data. Data can be manually validated against each other to help identify if certain types of deaths are more likely to be captured in one system than the other, and to improve the quality of data in both systems.
  3. **Linking unit-record data.** Record linkage, the process of identifying and linking records that belong to the same person, so that records found in one system but not the other can be used for validation of data quality for both systems, and/or included in some form in both systems to improve coverage and thus data quality.

- **Stage two - analysis and design. Outlines three critical steps in the analysis and design of data integration:**
  1. Developing business process maps of critical information pathways.
  2. Defining data needs for key stakeholders.
  3. Defining the scope and objectives of data integration.
- **Stage three - implementation planning.** Discusses common issues and challenges countries are likely to face during implementation, and key considerations when integrating data from CRVS and MPDSR systems, including human resources, finance, infrastructure, information technology (IT) systems and quality assurance processes.

It is strongly recommended that users keep a record of answers to key questions and any decisions made on data integration while working through the stages. A **planning template** is included in **Annex 1**, which collates basic information on the proposal. Do not worry if the document is incomplete or if stakeholders do not have all the answers at the start, as the template may need to be revised or updated as discussions progress. Once users have worked through all the stages in the guidance note and updated the template, the planning summary will become the basis for moving forward.

# Flowchart - Planning stages for integrating data from CRVS and MPDSR systems.

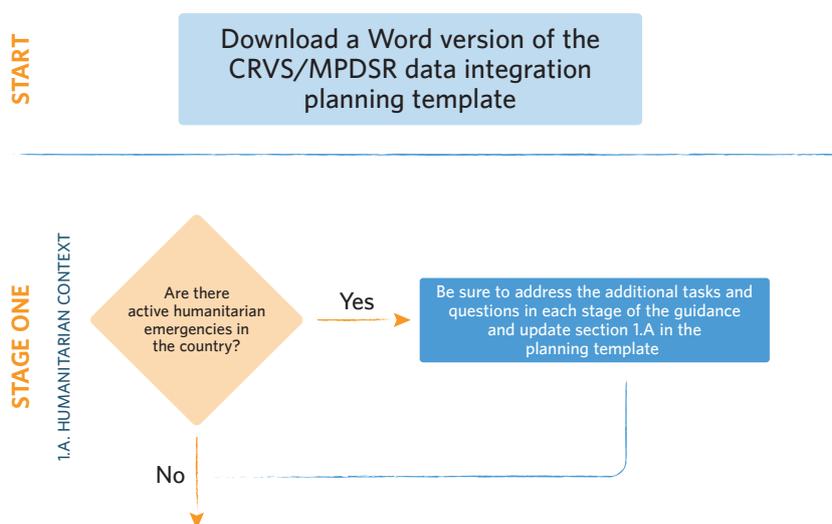




## Stage one – preparation

Stage one examines any existing humanitarian emergencies in the country, along with an assessment of existing legal frameworks, coordination mechanisms and robustness of the CRVS and MPDSR systems. *Note that countries that do not have active humanitarian emergencies do not need to complete section 1.A on the humanitarian country context.*

### 1.A. Are there active humanitarian emergencies in the country?



Information management in humanitarian settings is vastly different, and as such, there are additional challenges in the registration of births and deaths and in the establishment of mortality surveillance systems more generally. Importantly, not all groups experience disadvantages the same way – there are, for example, different barriers to registration for IPDs, to people from another country; protracted humanitarian emergencies also have a vastly different impact than temporary ones, while the restricted freedom of movement imposed on people living in refugee camps means that their barriers (and opportunities) to registration are different to those living in the community (35); Camp settings often lack mechanisms for the safe storage of records (36), along with uncoordinated and fragmented collection of data from the various sources (37).

The acute stage of humanitarian emergencies generally refers to the first six months post-disruption, when functionality of the health system, and more broadly, the government, is very weak (38). The early acute phase is characterised by severe disruption to everyday life, with government agencies and partners immediately involved in responding to the crisis. There may be

restricted access to health care data due to security concerns, along with a lack of clarity and understanding among agencies around their roles in the CRVS and MPDSR systems, leading to incomplete data. The late acute phase is characterised by less disruption, with some systems functional or semi-functional (38). Surveillance often remains expensive and difficult to implement, with a low priority assigned by non-governmental organisations (NGOs) and a lack of follow-up, particularly among population groups with high mobility. The time-consuming nature of the review process and lack of a functional review committee may mean that a full review is not feasible in every situation (38). In protracted humanitarian settings, while the initial emergency may be over, health systems generally remain weak, resulting in lack of records and medical files needed for CRVS and MPDSR systems, along with poor quality data overall due to limited opportunities for training in data collection (38). The political will and ability to support registration and mortality surveillance in conflict areas, or among refugees, asylum seekers and IDPs may also decline, particularly as aid agencies reduce support for the country, or withdraw entirely (38).

Questions to consider if there are active humanitarian emergencies in the country:

### **1.A.1. What phase of the humanitarian emergency is the country in?**

Overall, CRVS and MPDSR systems are difficult to implement and/or sustain in the absence of a functional government, and systems may need to be adapted and simplified to suit the humanitarian setting. MPDSR Systems cannot be applied uniformly in humanitarian settings, and this will have an impact on when and how integration with CRVS can be implemented (38). During the acute phase, for example, focus should be on rapid surveillance and establishing basic health services rather than establishing full MPDSR systems. In protracted humanitarian settings, attention can be shifted to opportunities for strengthening CRVS and MPDSR systems by developing processes to aggregate data from different sources, standardising patient records and documentation and strengthening the system for the identification of deaths (38). MPDSR systems may be implemented in health facilities first before moving out into communities.

### **1.A.2. What proportion of refugees, asylum seekers and IDPs are living in host-communities? What proportions are living in camp settings? What proportions are living in informal settings? If available, information on the proportion of women of reproductive age living in each setting should be used.**

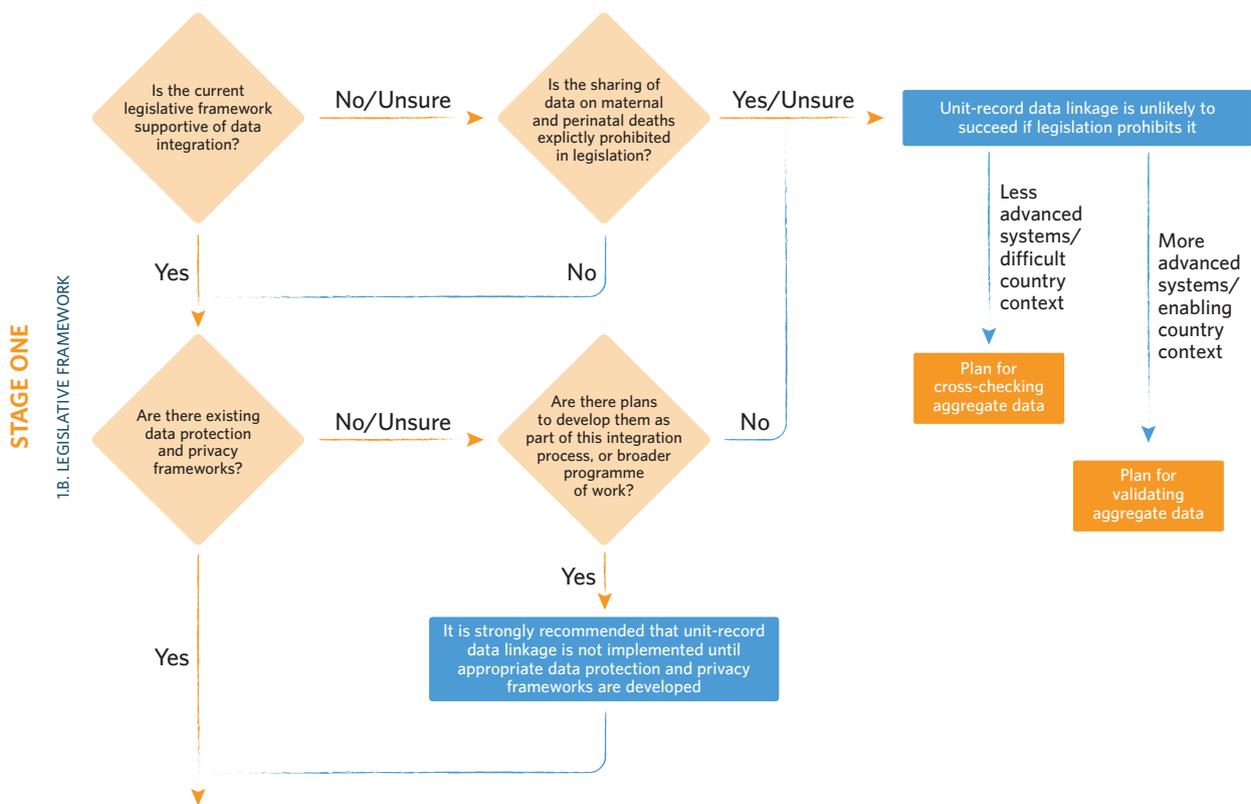
In camp settings, the level of implementation of CRVS and MPDSR systems will rely on the availability of registration and health systems and outreach services (38). It should be noted that refugees living in camps may have better access to health care through humanitarian agencies than IDPs or refugees living in the community (39). Within camps, there is generally functioning power and water supplies, and facilities generally have functioning referral systems for obstetric emergencies; while community facilities have weaker or non-functional referral mechanisms, along with longer distances to facilities for those living in remote communities (39). Access to services for refugees, asylum seekers and IDPs living in informal settings is generally much more difficult, as such settings are often not integrated into government services, and given their informal nature, are often transient with limited support from humanitarian aid agencies.

### Key resources

- *Maternal Death Surveillance and Response: Inventory of current practices in humanitarian settings supported by UNFPA* (forthcoming).
- *Birth registration in emergencies: a review of best practices in humanitarian action* (Plan International 2014), available at:  
[https://www.ohchr.org/Documents/Issues/Children/BirthRegistrationMarginalized/PlanInternationalGeneva\\_5.pdf](https://www.ohchr.org/Documents/Issues/Children/BirthRegistrationMarginalized/PlanInternationalGeneva_5.pdf)

**Before continuing:** Update the CRVS/MPDSR data integration planning template.

## 1.B. Is the current legislative framework supportive of data integration?



Before assessing the technical interoperability of any digital databases used in CRVS or MPDSR systems (40), it is important to first assess if there are provisions in current legislation that allow (or prohibit) the sharing of data between agencies. Do government laws, for example, require that maternal and perinatal deaths identified in the MPDSR system are shared with civil registration? Are MPDSR systems only able to share de-identified data? Is the CRVS system obliged to share its data with any other government agencies – including national statistical offices? Country offices may find that current legislation is mostly ‘silent’ around data integration, as opposed to actively allowing or prohibiting the practice. If this is the case, supporting the development of data sharing agreements that clearly outline the roles and responsibilities of concerned agencies and define the data to be shared (including when and how) should form a core component of future data integration processes.

Before implementation, also be sure to check if there is a data privacy and protection framework in place to ensure data associated with CRVS and MPDSR systems are protected from external risks and breaches through all steps during data integration (**Box 3**) (9). Practical questions in assessing the risks associated with data sharing include (41):

**1.B.1. Will the integrated data contain personally identifiable information?****1.B.2. Is the amount of data being integrated proportional to the needs of the project?**

Consider if the purposes for which the data can be used are clearly documented or defined. While the idea of sharing as much data as possible and keeping it for as long as possible, in order to do as much good as possible, may seem acceptable – it is not. Many statistical agencies refer to this as the principle of necessity and proportionality: only collecting enough data that is necessary and proportional to what the project or organisation wants to achieve (42).

**1.B.3. Is the level of data protection afforded by all government agencies equal?****1.B.4. What processes and safeguards have been implemented to ensure any data protection rules or privacy requirements applicable to the data are upheld during and after integration?****1.B.5. Is there legislation that prohibits data sharing between government agencies?****1.B.6. Are there plans and processes in place to identify security breaches or disclosures of personal information in error?**

### Box 3. Privacy impact assessments

Concerns about data privacy and security are significant ethical issues raised by data integration, particularly as direct consent will not have been obtained from the individuals whose data are being shared, and as integrated data may become personally identifiable (2). While there are several technical methods to limit the release of personal identifiers for data integration (particularly unit-record linkage), referred to as privacy-preserving record linkage (PPRL) (43), an important first step in any integration project should be the development of a privacy impact assessment (PIA). A PIA is a systematic assessment of a project that identifies the impact the project might have on the privacy of individuals, and sets out recommendations for managing, minimising or eliminating that impact.

PIAs are an important component in the protection of privacy and should be part of overall risk management and planning processes. Undertaking a PIA can assist agencies and partners to:

- describe how personal information flows in a project;
- analyse the possible impacts on individuals' privacy;
- identify and recommend options for avoiding, minimising or mitigating negative privacy impacts;
- build privacy considerations into the design of a project; and
- Achieve the project's goals, while minimising the negative and enhancing the positive privacy impacts.

More information on PIAs, including a short online course, is available at:

<https://www.oaic.gov.au/privacy/guidance-and-advice/guide-to-undertaking-privacy-impact-assessments/>

### Key resources

- The *EU Charter of Fundamental Rights* (available at: [https://ec.europa.eu/info/law/law-topic/data-protection/data-protection-eu\\_en](https://ec.europa.eu/info/law/law-topic/data-protection/data-protection-eu_en))  
*is an example of good practices regarding the processing of personal data.*
- The *Data linkage requirements* website of the State Government of Victoria (Australia) is a good example of the various data security and privacy standards that must be met before linkage projects can proceed in the state. Available at: <https://www2.health.vic.gov.au/about/reporting-planning-data/the-centre-for-victorian-data-linkage/for-researchers/vdl-data-linkage-project>

## Considerations for humanitarian settings

While it is important to consider data privacy and security in all settings, the issue is even more critical in humanitarian settings, with legitimate risks to personal security for refugees, asylum seekers, and IDPs. Concerns over how personal data are stored, and who they are shared with can reduce the likelihood of families to register a birth or death, for fear of reprisal. When there are multiple governments, for example, data can be used against citizens or specific ethnic groups associated with the opposition. Similarly, those residing in a country irregularly may not want to disclose their personal information. For many populations, there is also a reluctance to notify authorities around the registration of vital events for fear of negative consequences, such as forced deportation or reduced family rations.

In thinking about who can access data on maternal and perinatal deaths (and any other associated personal information) occurring in humanitarian settings, consider the following:

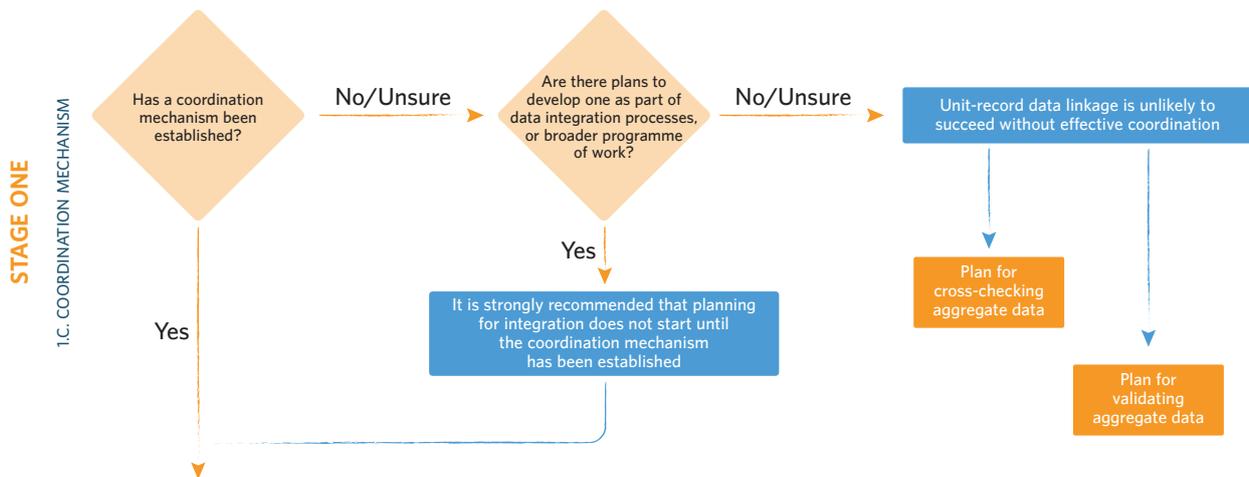
- Who will have access to the data? How will access be controlled?
- Who will have access to categories of personal information?
- Will unique identifiers be used?
- Are the security measures appropriate for the sensitivity of information recorded?
- Are there contingency plans and mechanisms in place to identify security breaches or disclosures of personal information in error?

### Key resources

- *Guidance on the Protection of Personal Data of Persons of Concern to UNHCR* is available at <https://www.refworld.org/docid/5b360f4d4.html>
- The *Handbook on Data Protection in Humanitarian Action* is available at <https://rm.coe.int/handbook-data-protection-and-humanitarian-action-low/168076662a>

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## 1.C. Has a coordination mechanism been established?



A coordination and oversight mechanism is required to ensure effective communication and coordination between agencies, with key stakeholders from the CRVS and MPDSR systems, and those engaged in humanitarian settings where appropriate. The coordination mechanism may operate within a high-level CRVS or MPDSR committee, or sub-committee on mortality and cause of death, or taskforce on maternal and perinatal deaths (28) – this will depend on existing structures and resources available. To ensure the mechanism can function effectively, clear terms of reference (TORs) must be developed and endorsed (**Box 4**), and members must have the authority to make decisions on behalf of their agencies.

The function of the committee or taskforce is to prepare the work plan and time schedule for data integration (establishment and ongoing processes), keep the various agencies informed and ensure their ongoing support, and to delegate roles and responsibilities among team members in the short- and long-term (44).

Questions to consider:

### 1.C.1. Who are the key stakeholders in the CRVS and MPDSR systems?

An essential first step in establishing an effective coordination mechanism is to conduct a detailed stakeholder mapping exercise (Box 4). Stakeholder mapping can help identify essential partners and clarify their current and potential contributions to CRVS and MPDSR systems, and future data integration.

### 1.C.2. Are there existing coordination mechanisms that could be utilised?

As part of stakeholder mapping, it is important to identify any existing coordination mechanisms that could either be used to oversee the data integration, or that need to be included in any ongoing discussions.

### 1.C.3. Are there champions from each of the main agencies who could help to advocate for the development of coordination mechanisms?

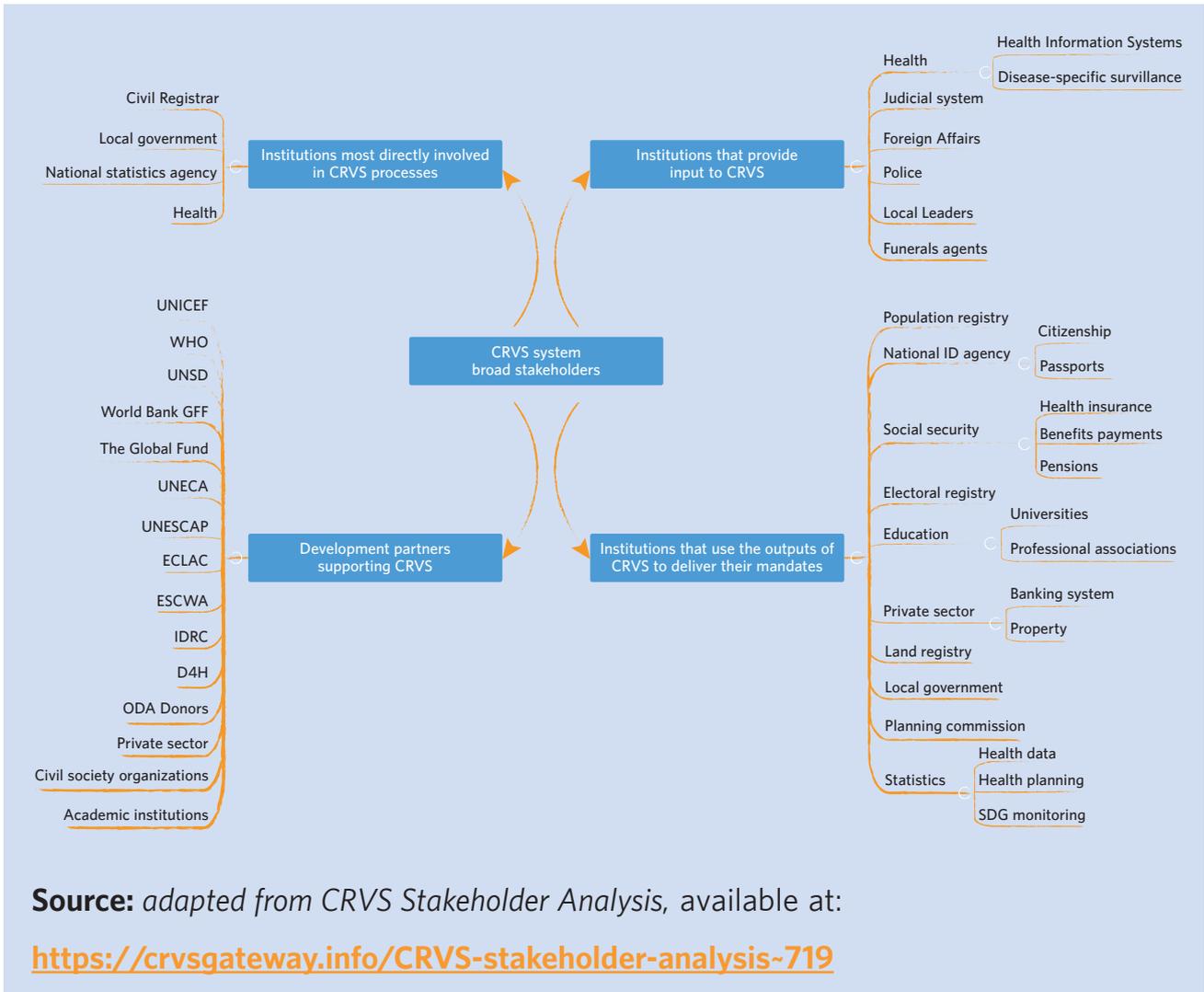
#### Box 4. CRVS stakeholder mapping

While civil registry offices and health facilities are often identified as key stakeholders, many other agencies and entities have roles to play in contributing to functional aspects of CRVS. Many other agencies also benefit from the statistical, legal, and administrative outputs of a CRVS system. Stakeholder mapping can help identify essential partners and clarify their actual and potential contributions to the overall performance of the CRVS system.

Stakeholder mapping in its simplest form is accomplished by facilitated group brainstorming to identify stakeholders, which can then be organised graphically with a mind-mapping tool. The diagram below shows a typical mind-map of CRVS stakeholders, organised by the roles they play:

- **Direct contributors** to CRVS processes, such as the civil registry, the national statistics agency and health facilities involved in the notification of vital events.
- **Providers of inputs** to the CRVS system, such as judicial authorities, the police, funeral agencies and local leaders - who can provide additional information on births and deaths.
- **Users of the outputs** of the CRVS system to deliver their mandates such as the national identification agency, population registry, social security, electoral registers, education, health, the private sector, non-government organisations and civil society.
- **Development partners** working to support CRVS system development.

Stakeholder analysis is a necessary step in preparing to apply enterprise architecture and business process mapping to CRVS systems. Note that in detailed CRVS process mapping, individuals, families, and community structures are also stakeholders because they benefit directly from the legal outputs. A generic example of national-level CRVS stakeholders, both suppliers and users, mapped by broad institutional level is provided below.



## Key resources

- Information on establishing a CRVS coordination committee is available at:  
<https://crvsgateway.info/CRVS-coordinating-committee~330>
- “The Maternal Death Surveillance and Response Technical Guidance” developed by the World Health Organization contains detailed guidance on establishing a maternal death review committee, along with an example committee worksheet and MDSR implementation planning tool. Download a copy from:  
[https://apps.who.int/iris/bitstream/handle/10665/87340/9789241506083\\_eng.pdf](https://apps.who.int/iris/bitstream/handle/10665/87340/9789241506083_eng.pdf)
- Several practical resources are available in Making Every Baby Count: Audit and review of stillbirths and neonatal deaths (WHO 2016), including how to set up a mortality audit steering committee, code of practice declaration, and meeting minutes and action form. Download a copy from  
<https://apps.who.int/iris/bitstream/handle/10665/249523/9789241511223-eng.pdf?sequence=1>

## Considerations for humanitarian settings

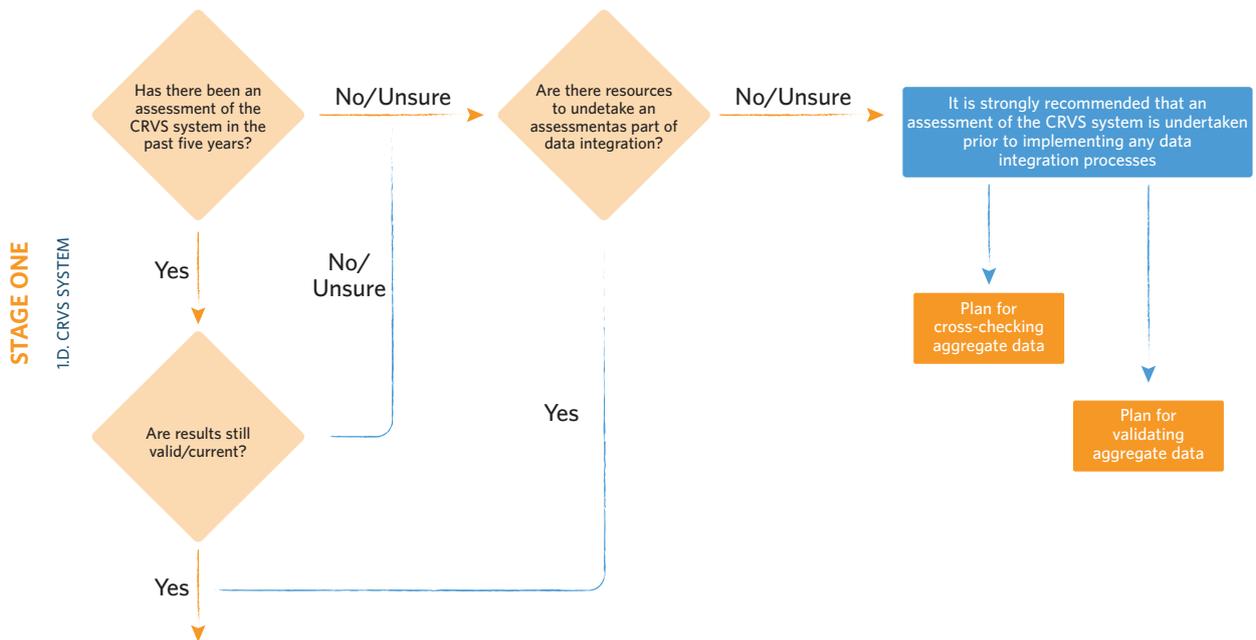
Given the number of agencies involved in humanitarian response, from bilateral partners (country governments), multilaterals (UN partners), NGOs and the military, a strong central coordinating mechanism is critical (45).

Additional questions to consider:

- Who are the key stakeholders involved in the registration of births, deaths and more generally mortality surveillance in humanitarian settings in the country?
  - What role do they play?
- Are there current coordination mechanisms in place linking aid agencies involved in the humanitarian response to the national government?

**Before continuing:** Update the CRVS/MPDSR data integration planning template

## 1.D. Has there been an assessment of the CRVS system in the past five years?



Understanding current strengths and weaknesses of the CRVS system is critical before implementing processes for data integration. While this question refers to assessments that have been conducted in the past five years – if there have been recent significant disruptions to the routine functioning of the CRVS system, these should be taken into consideration, as any assessments done prior to the disruption are likely to over-estimate current capacity. Two of the most widely used assessment methodologies are the CRVS Rapid and Comprehensive Assessments developed by the WHO (see ‘Key resources’). While both assessments review several components of the CRVS system, those with the most impact on data integration between CRVS and MPDSR systems are outlined below. For all these questions, if there are known sub-national level disparities in the country (such as between urban and rural areas, or different population groups), it is important to note how this may impact on different aspects of the CRVS system, such as coverage or completeness, or quality of medical certification of cause of death.

### 1.D.1. CRVS system overview

- 1.D.1.1 What was the WHO Rapid assessment overall score and system classification for the country (if applicable)?
- 1.D.1.2. What areas of the rapid assessment (as they relate to MPDSR systems) did the country score lowest in?

### 1.D.1.3 Is the CRVS system primarily paper-based or electronic?

- For systems that are electronic, at what point during data collection is data entered into the electronic system (i.e. at the health facility level, regional level or national level)?
- Do other agencies have access to the CRVS system (if electronic)?
- Are there opportunities to automate the reporting/notification of deaths, so that both the CRVS and MPDSR systems receive real-time data on deaths? This may include the establishment of registry offices in hospitals and major health facilities (12, 24), or providing health facilities with direct access to shared registry databases (Box 5). Note that while this will provide more complete data on deaths by (at minimum) age and sex; it may not be able to accurately identify maternal deaths or provide data on cause of death or outcomes from the MPDSR review process.

**Note:** *WHO Comprehensive Assessment questions that cover topics 1.D.2.-1.D.6 are listed in the project planning template in Annex 1 for ease of use.*

### 1.D.2. Legal basis and resources for civil registration.

- Understanding if maternal and perinatal deaths are classified as 'notifiable' events in CRVS legislation and the extent deaths are 'actively' identified (11, 27). Active case-finding methods include using a range of sources for the identification of deaths, including village authorities, community informants, volunteers, outreach workers and survey and surveillance systems; the use of mobile messaging technology; and linking to burial and cemetery systems/permits (28).
- The extent that data from CRVS and MPDSR can be linked is heavily dependent on both systems using standardised terminology and definitions – do both systems, for example, use the same definitions for a live birth, maternal death or foetal death/stillbirth? Are these terms applied uniformly across the country?
- Does civil registration law clearly designate the functions, duties and responsibilities of each government agency or department involved? Ensuring these are clearly defined is critical before integration takes place, to ensure that the right data is being shared with the appropriate agency – and that data is not being unnecessarily shared, increasing privacy and security risks and concerns.

### **1.D.3. Registration practices, coverage, and completeness**

- An important prerequisite in linking both systems is to ensure that the data being collected are standardised both within and between each system. This includes the use of standard forms that clearly define key terms to identify, notify, review and respond to deaths (18, 22). Training in the International Classification of Diseases (ICD), particularly the ICD-PM (for perinatal deaths) and ICD-MM (for maternal deaths), allows for comparability in the collection, processing, classification and presentation of mortality statistics, which helps to ensure cause of death data are useful and standardised (6, 24, 46). Data integration often also requires a national data repository of events, and at a minimum, accurate and consistent reporting of key variables (name, date of birth, health facility of occurrence, etc.) to allow for cross-validation (30).
- Are the same data on births and deaths collected across the country and at every level of the CRVS system (including state or provincial, national and local levels)?
- Is cause of death included on the death registration form? If not, is information about the cause of death collected at the same time as the death is registered, but using a different form?
- Are computers used at any stage of the birth and death registration process? Are computers used for any or all data compilation, transmission, validation and storage? The level of digitisation of the CRVS system will have a significant impact on how and when integration with the MPDSR system can occur.

### **1.D.4. Death certification and cause of death**

- Is the International Form of Medical Certificate of Cause of Death used for: all deaths; only deaths occurring in hospitals not for those taken place outside hospitals; only deaths occurring in some specific hospitals, such as university or regional hospitals; other deaths? Do physicians know how to correctly complete the death certificate, including the causal sequence and the underlying cause?
- Does the death certificate state whether a woman was pregnant, or had recently been pregnant? Are maternal deaths reviewed separately from other deaths?

### **1.D.5. ICD mortality coding practices**

- Is cause of death coding done from a copy of the original death certificate or from a transcribed list provided by the civil registration office, or from some other summary document? Is

all the information on the death certificate coded, or only the presumed underlying cause of death?

### 1.D.6. Data access, use, and quality checks

- Are fertility rates and mortality ratios derived from CRVS compared with rates derived from other sources? Comparing both the number of deaths and key indicators such as the MMR, PNMR and NMR between the CRVS and MPDSR systems (as well as with estimates from household surveys and the census) is an important step in understanding how well each system is capturing deaths, and as such, the type of integration required.

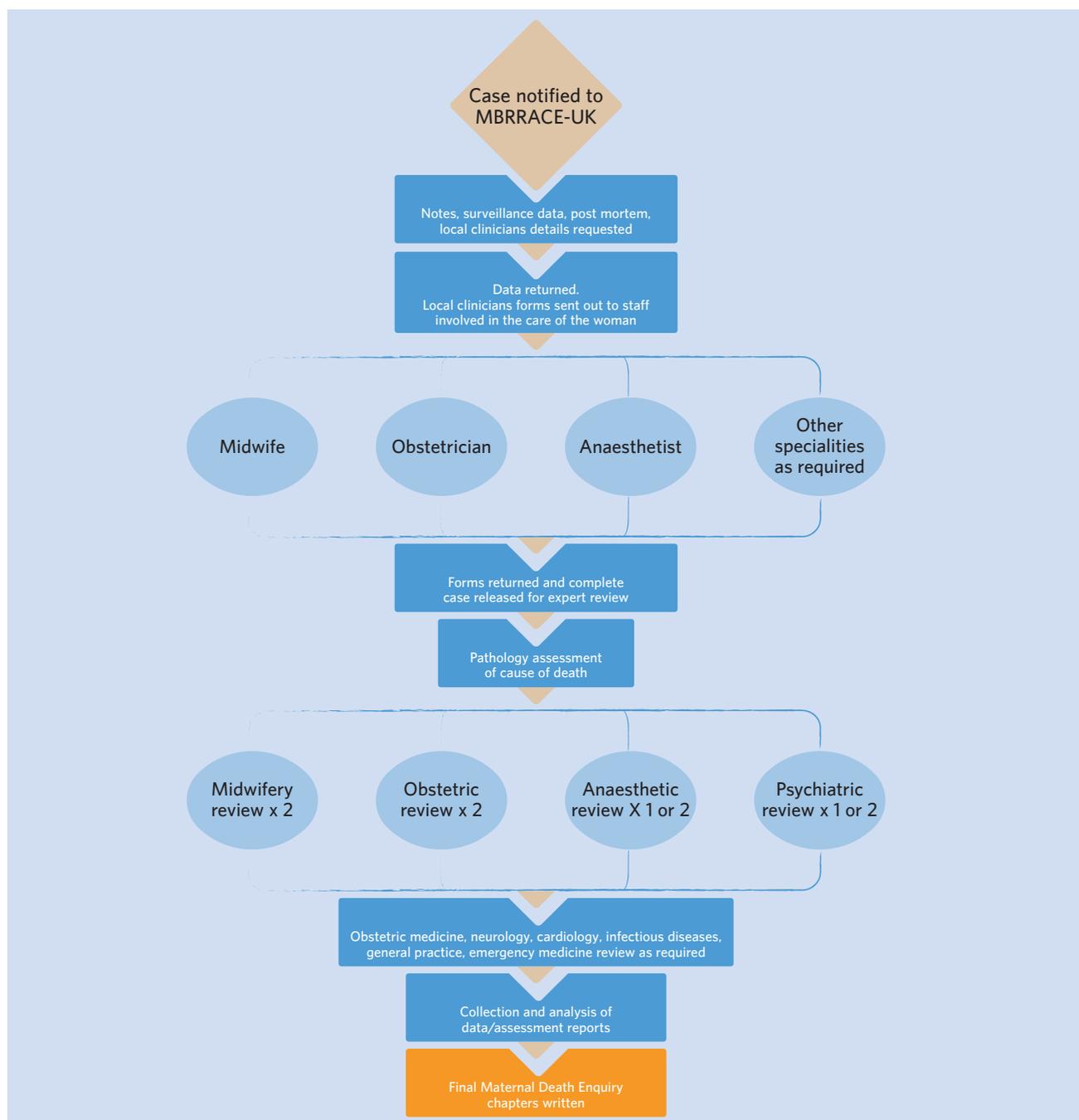
#### Box 5. Experiences with mortality surveillance in the United Kingdom

The United Kingdom's National Confidential Enquiry into Maternal Deaths (CEMD) was established in 1952 and is considered a global reference standard in terms of best practice for the surveillance of maternal mortality.

An electronic maternal and perinatal mortality notification system has been deployed in hospitals across England, Scotland, Wales and Northern Ireland. The web-based portal allows hospital staff to notify eligible deaths by completing an electronic form and uploading it to the system. This ensures instant notification of deaths across the whole United Kingdom and ensures high-quality data on every case. The system also has a secure web-based case-note viewing system, which allows staff to view relevant files including medical notes, post-mortem results and probable cause of death.

Another innovation of the system is the linkage of birth data from civil registration with death certificates from adult females, to ensure late and indirect maternal deaths are not missed by the system.

**Source:** *adapted from Kurinczuk et al (47)*



## Key resources

The CRVS Comprehensive Assessment reviews the main aspects of CRVS systems, including the legal and regulatory framework; registration, certification and coding practices; and the compilation, tabulation and use of the resulting data. The Rapid Assessment was developed to support countries in developing an understanding of the strengths and weaknesses of their CRVS system by providing an overall summary score, based on a limited number of key questions. Both assessment tools are available at:

[https://www.who.int/healthinfo/topics\\_standards\\_tools\\_data\\_collection/en/](https://www.who.int/healthinfo/topics_standards_tools_data_collection/en/)

## Considerations for humanitarian settings

Systems of civil registration are generally severely weakened during humanitarian emergencies or cease to function entirely. Further, when there are multiple governments or systems of governance, registration documents issued by one may not be recognised by another. Results from national CRVS assessments may not fully capture the strengths and weaknesses of the system as it currently operates in humanitarian settings. Depending on the national legislative framework, the vital events of non-citizens may also be more difficult to capture.

Additional questions to consider:

- Legal basis and resources for civil registration
  - How are the vital events of non-citizens (refugees, asylum seekers, IDPs) registered in the system? Are their events recorded in the same register as citizens, a different register, or not at all?
  - Is the population covered by civil registration laws clearly defined? Is it, for example: the entire population living in the country; only citizens living in the country; some other subsets of the population?
  - What does the law require in relation to registering births and deaths of citizens living abroad?
  - What does the law require in relation to registration of births and deaths of: foreign nationals living in the country; nomadic or displaced populations; refugees and asylum seekers; and those who cannot prove their nationality?
  - What role do non-state actors play in registration?
- Registration practices, coverage and completeness
  - Are there some vital events that cannot be registered through the normal system?
  - What subpopulations are most likely to be undercounted in vital registration? (Note: undercounting may be different for births and deaths.)
  - Are registration processes or requirements (identity documents, need for a male relative, etc.) prohibitive to certain populations?

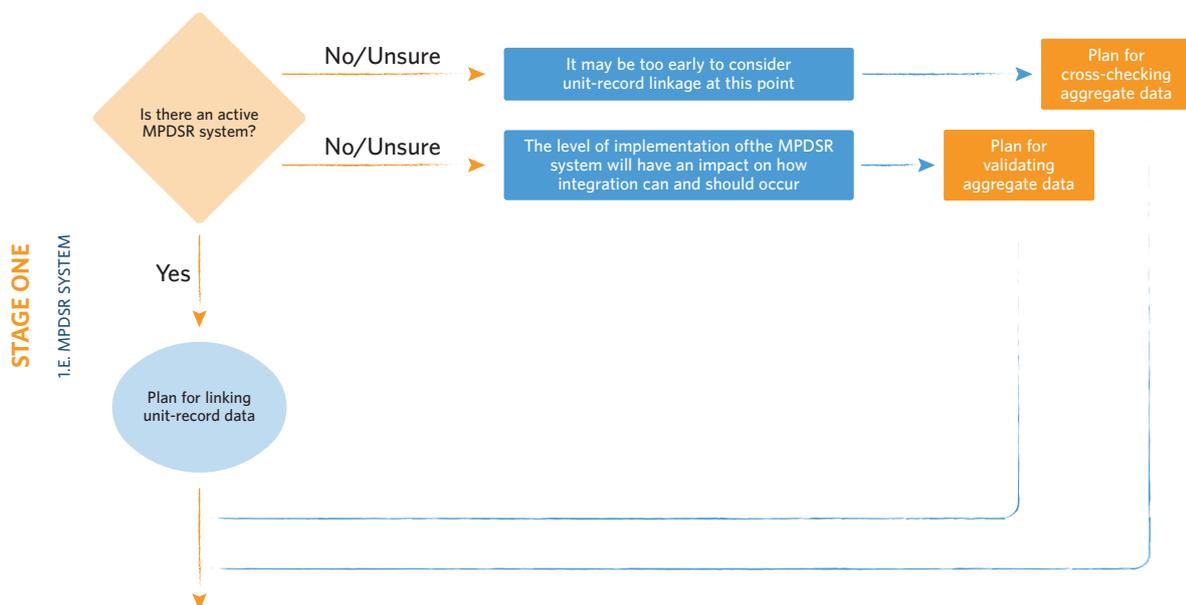
## Key resources

- The Bali Process Civil Registration Assessment Toolkit provides a structured methodology for assessing legal and registration procedures, identifying any prohibitive laws, processes or requirements that may prevent refugees, asylum seekers, IPDs, and persons of undetermined nationality from registering their vital events – with the goal of developing a national strategic plan to address these barriers, and measure improvements in registration. The toolkit can be downloaded from

<https://www.baliprocess.net/UserFiles/baliprocess/File/Bali%20Process%20Civil%20Registration%20Assessment%20Toolkit%20FINAL.pdf>

Before continuing: Update the CRVS/MPDSR data integration planning template

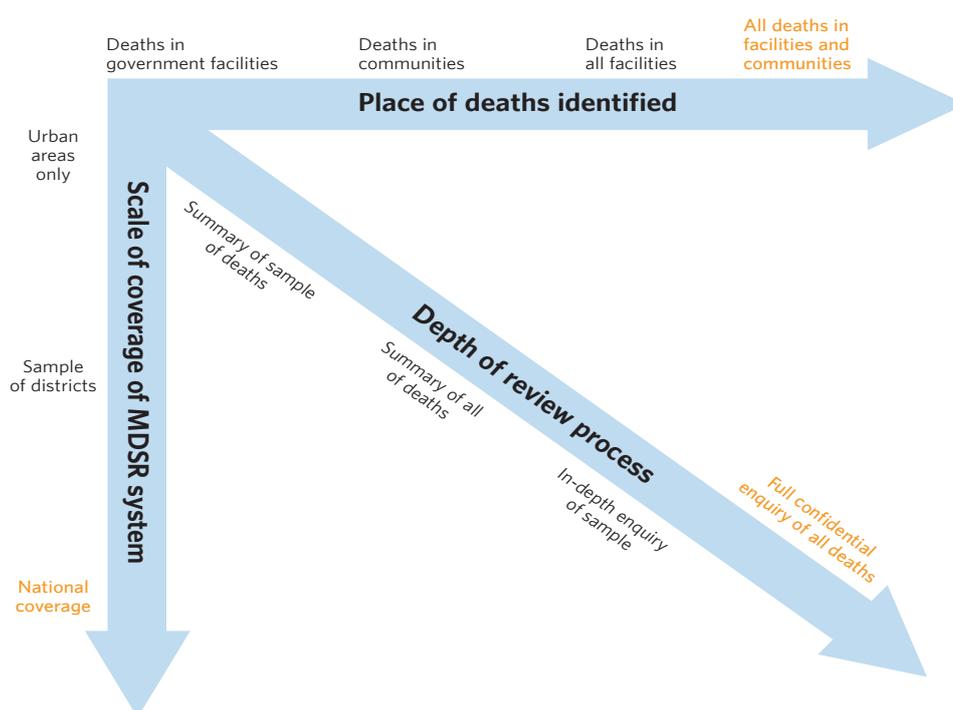
## 1.E. Is there an active MPDSR system?



The level of implementation of the MPDSR system naturally has an impact on the extent of integration with the CRVS system. For MPDSR systems that are only partially established or generally considered ‘weak’, it may be best to consider implementing basic data integration, such as cross-checking aggregate numbers of maternal and perinatal deaths. For systems that are active and well-established, integration may be more detailed and complex. In classifying the level of implementation of the MPDSR system, it may be useful

to refer to the diagram developed by the WHO and partners (Figure 3), which defines three key aspects of a MDSR system: place of deaths identified, depth of review process, and scale of coverage. Note that level of implementation may differ between maternal and perinatal deaths, and in humanitarian settings.

**Figure 3:** Main dimensions for a phased introduction of a maternal death surveillance and response (MDSR) system



Source: WHO, 2013 (4)

Additional questions to help understand the health information infrastructure of the MPDSR system include (18, 24, 48):

### 1.E.1. Is there a national policy to notify and review all maternal and perinatal deaths?

1.E.1.1. Is there a national MPDSR plan?

1.E.1.2. What proportion of estimated maternal and perinatal deaths is notified?

### 1.E.2. What components of MPDSR are already in place and where?

1.E.2.1. What are the aims and purpose of MPDRs?

1.E.2.2. Who are the actors engaged in the process?

1.E.2.3. How are they carried out?

1.E.2.4. What information is recorded on each death?

### **1.E.3. Where are deaths identified from as part of the system?**

- 1.E.3.1. Does this include 'unofficial' sources such as funeral homes, community workers, religious leaders, etc.?
- 1.E.3.2. What proportion of deaths is estimated to be notified from health facilities and from the community?

### **1.E.4. What is the depth of the review process?**

### **1.E.5. What is the scale of coverage of the system?**

### **1.E.6. Is the MPDSR system primarily paper-based or electronic?**

- 1.E.6.1. For systems that are electronic, at what point during data collection is data entered into the electronic system (i.e. at the health facility level, regional level and national level)?
- 1.E.6.2. Do other agencies have access to the MPDSR system (if electronic)?
- 1.E.6.3. Are there opportunities to link or cross-check maternal death databases (if they exist) with civil registry databases? In several countries, for example, when the MPDSR system identifies a death and upon cross-checking with civil registration finds it has not been registered, a 'placeholder' death is recorded in the CRVS system. This placeholder helps to improve the completeness of mortality statistics. However the death event itself is not officially registered until all legal requirements regarding the registration of a death are met. While such integration or cross-checking will ensure that only data on maternal and perinatal deaths are shared with the CRVS system, the data may take longer to receive and has the potential to include duplicates (especially for systems that do not have unique ID numbers for each death).

### **1.E.7. Is there a national committee for maternal and perinatal deaths? Is there a sub-national committee?**

- 1.E.7.1. How often do committees meet?
- 1.E.7.2. What is the membership composition of the committees?

### **1.E.8. If more than one system that reports maternal and perinatal deaths is currently in place, how do these systems interact?**

### **1.E.9. Is there a system of integrated disease surveillance and response (IDSR) in place, and if so, does it report the number of maternal deaths?**

## Key resources

- *Maternal Death Surveillance and Response Technical Guidance* developed by the World Health Organization, available at:  
[https://apps.who.int/iris/bitstream/handle/10665/87340/9789241506083\\_eng.pdf](https://apps.who.int/iris/bitstream/handle/10665/87340/9789241506083_eng.pdf)
- *Making Every Baby Count: Audit and review of stillbirths and neonatal deaths* (WHO 2016), available at:  
<https://apps.who.int/iris/bitstream/handle/10665/249523/9789241511223-eng.pdf?sequence=1>
- The Maternal and Child Survival Program, USAID, has conducted several assessments of MPDSR implementation globally. The assessments are based on key informant interviews with MPDSR focal points and other key informants, which are then used to develop a score from 0–30 to determine the stage of MPDSR implementation. An example of their work in Tanzania, which includes a detailed methodology, key informant questionnaire and implementation scoring scheme, is available at:  
[https://www.mcsprogram.org/resource/assessment-of-maternal-and-perinatal-death-surveillance-and-response-mpdsr-implementation-in-kagera-and-mara-region-tanzania/?sfm\\_resource\\_country=tanzania](https://www.mcsprogram.org/resource/assessment-of-maternal-and-perinatal-death-surveillance-and-response-mpdsr-implementation-in-kagera-and-mara-region-tanzania/?sfm_resource_country=tanzania)

## Considerations for humanitarian settings

Given the challenges with information management more broadly, and the specific barriers to implementing systems of MPDSR in humanitarian settings, data integration may look quite different in humanitarian settings than for the rest of the country. Important questions to consider include:

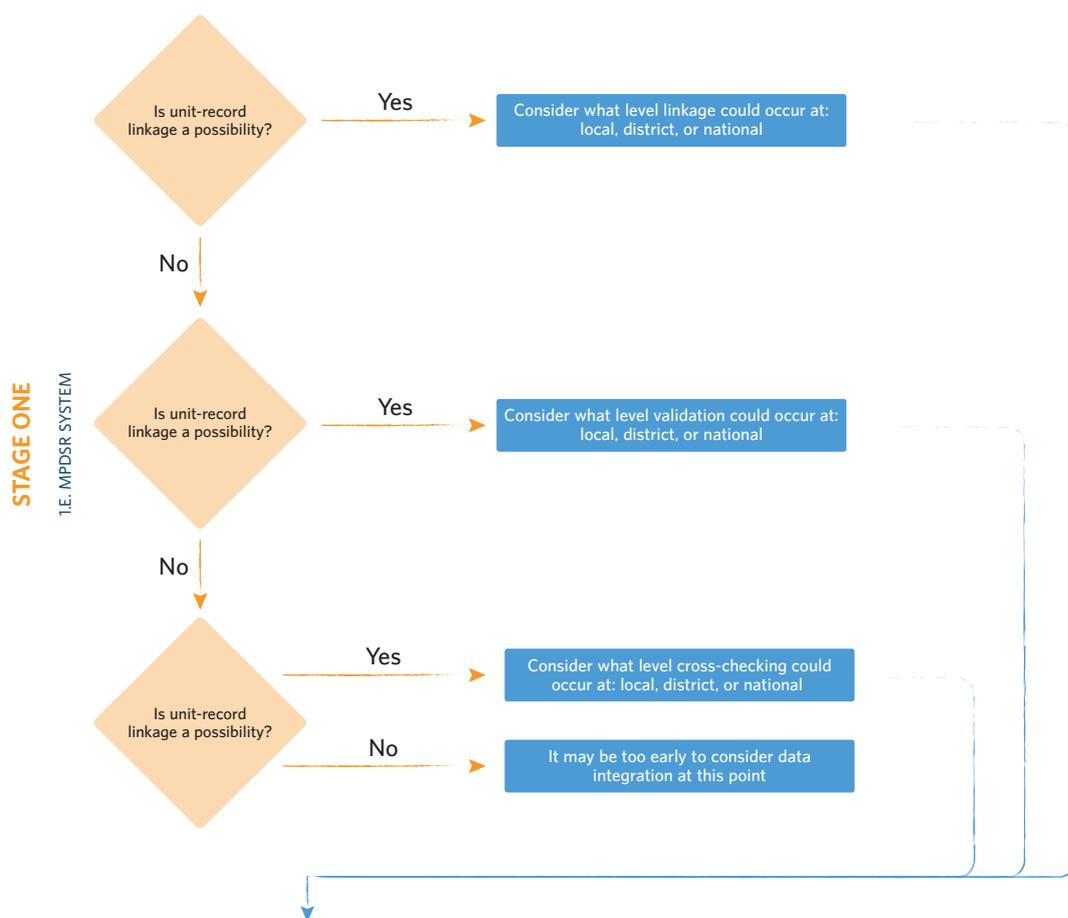
- Are there established systems of MPDSR in humanitarian settings in the country  
In their recent assessment of MDSR systems in humanitarian settings, UNFPA (49) classified four different implementation scenarios, which could be applied to MPDSR:
  1. No operational system
  2. National system applied by the ministry of health with various degrees of support from other agencies
  3. MPDSR-like system led by a humanitarian working group or organisation
  4. Parallel systems where several humanitarian organisations are operating their own systems within the camp setting.
- What role do aid agencies play in mortality surveillance?  
UNHCR, for example, has developed and introduced a maternal death review report system in all refugee camps under its direct management (49). The system is used by teams to collect information on the demographic characteristics, pregnancies, and deaths of pregnant women. It collects both quantitative and qualitative information, including information on the three categories of delay and information on cause of death based on WHO guidelines (50).
- Are data on maternal and perinatal deaths shared with the national government, or government systems?

### Key resources

- Maternal Death Surveillance and Response: Inventory of current practices in humanitarian settings supported by UNFPA (forthcoming).

**Before continuing:** Update the CRVS/MPDSR data integration planning template

## 1F. Summarizing data integration possibilities



Based on the findings of parts 1A to 1E above, this section summarizes what types of data integration may be possible within a country. **This guidance defines three different types of data integration, ranging from basic to advanced:**

1. **Cross-checking aggregate data.** For countries with non-functional CRVS and/or MPDSR systems, those that are still in development or those with active humanitarian emergencies, this first level of integration is aimed at improving the collaboration and coordination between key agencies. Integration would likely involve agencies coming together once every six or 12 months to compare the number of maternal and perinatal deaths registered by civil registration to those recorded in the MPDSR system to assess potential under-counting in either system. While the recommended approach would be to conduct such cross-checking as a routine agenda item for the coordination mechanism (committee, task-force, etc.), if no such mechanism exists, or if there are significant barriers preventing agencies from working together, this could be done independently (for example, by the agency responsible for MPDSR comparing the number

of maternal and perinatal deaths recorded in one year with published data on deaths by age and/or cause from the civil registration system).

2. **Validating aggregate data.** At a technical level, data validation refers to the application of a series of yes/no questions on the accuracy and quality of data before it is further processed, imported or used, generally performed by specialised software packages (2). However, aggregate data on the number of maternal and perinatal deaths by key variables as captured by each system can be manually validated against each other to help identify if certain types of deaths are more likely to be captured in one system than the other, and to improve the quality of data in both systems. Cross-validating maternal deaths tabulated by age, cause of death, and place of usual residence, for example, may identify deaths captured in the MPDSR system but not civil registration, and visa-versa.
3. **Linking unit-record data.** Record linkage, the process of identifying and linking records that belong to the same person, is extensive, complex, and particularly challenging given the lack of unique identifiers used within and between various data systems (32). When linking unit-record data, there are two commonly used methods. Deterministic linkage is applied when there are one or more identifiers, such as a national identification (ID) number that will match completely with the other dataset(s). Probabilistic linkage is typically used when a unique identifier is not available and involves the matching of partially identifying variables, which may not be unique (such as name or date of birth). Agreement and disagreement weights for each variable are calculated according to standardized formulae. Thresholds of certainty around whether records are truly matched can be pre-determined to decide which links will be accepted as true matches and which will be rejected. Error rates can be pre-specified; however, this involves a trade-off between precision and sensitivity of data linkage (32). A combination of deterministic and probabilistic methods can also be used.

### Considerations for entry points within MPDSR systems

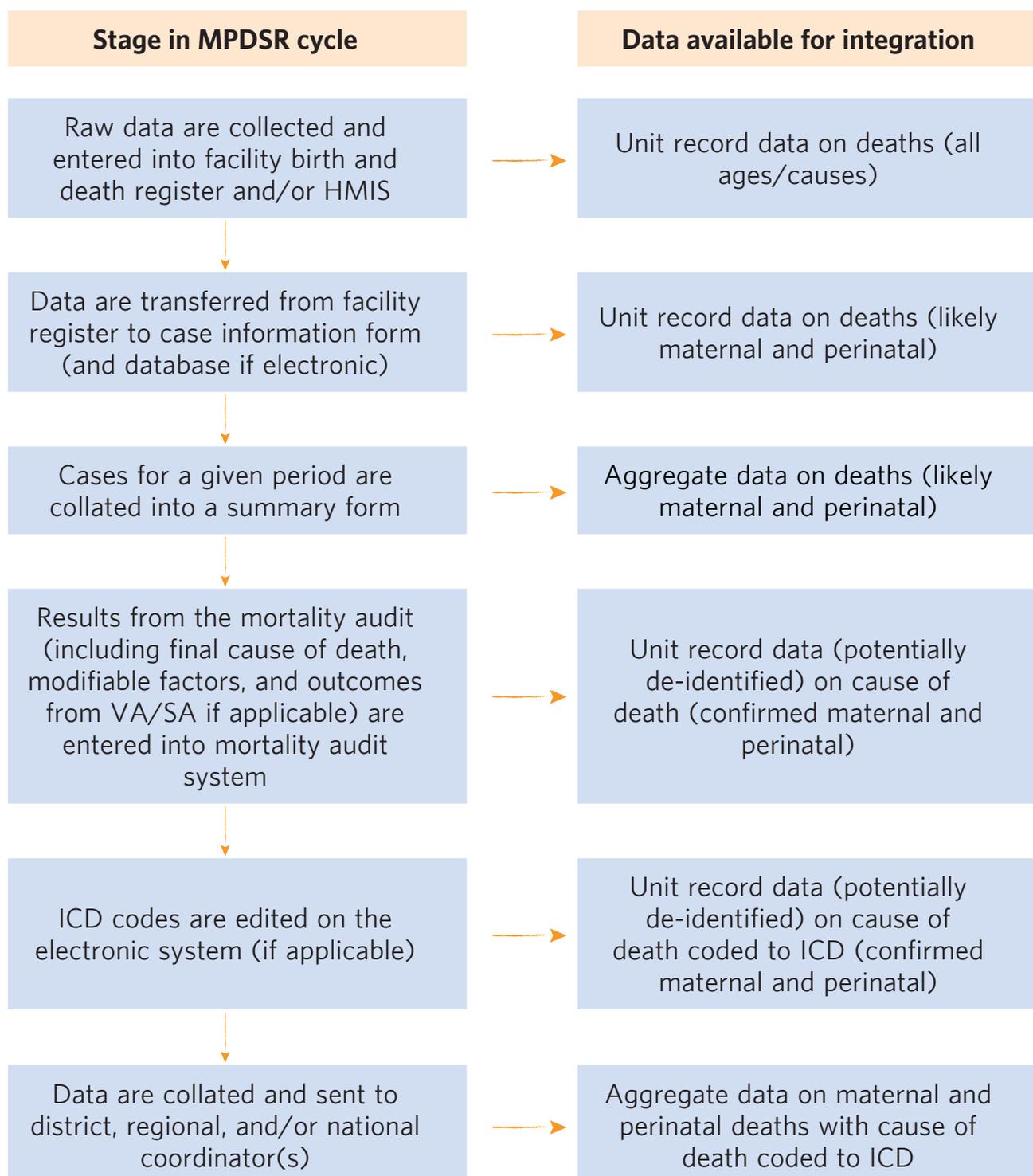
Data integration between CRVS and MPDSR systems can occur at a unit record or at an aggregate level. A good first step for many countries, for example, is to convene regular meetings where the total number of maternal and perinatal deaths captured in each system over a recent period are shared and discussed. This is particularly useful in highlighting the scope of potential under-registration of deaths within the CRVS system, and scope of potential missed deaths in the MPDSR system.

In considering the typical flow of data in the MPDSR process (Figure 3), each of the following events will have different integration opportunities:

- **Identification of a death event.** Integration at this point will provide data on all deaths (including those that may not ultimately be classified as maternal or perinatal). Depending on the forms and systems used, data may be at the unit-record level (with personal identifiers such as names and date of birth), which facilitates unit-record linkage between systems. However, deaths at this stage in the system most likely will not have had a certified or coded underlying cause of death assigned, nor will they have been through the audit process. Integration at this stage provides the possibility to provide a larger register of deaths to help complete the CRVS system – that is, all perinatal deaths and deaths occurring among women of reproductive age (not just those due to maternal causes). This provides a significant opportunity to minimise ‘missing’ deaths from within the civil registration system.
- **Transfer of data from register to case information form.** Integration at this point will provide data on deaths that have been identified as maternal or perinatal and will likely still be at the unit-record level.
- **Collation of data to summary form.** Integration at this point will provide aggregate data on the number of maternal and perinatal deaths in a given time period; however it will no longer include personal identifiers (apart from perhaps counts by age (maternal deaths) and age/sex (perinatal deaths)).
- **Results entered into mortality audit system.** The mortality audit system may be electronic, or data may be recorded on the initial case information form. By this stage in the process, the amount of information available around the circumstances leading to death will be very rich (including results from any verbal or social autopsies conducted). The death will likely have a medically certified cause associated with it, along with an ICD code. Data may no longer include all personal identifiers, as many MPDSR systems remove this information before the audit process, however information such as age and sex may still be recorded.
- **Codes edited on electronic system.** It is not uncommon for causes of death and their corresponding ICD codes to be changed as a result of the MPDSR process. Integration at this stage will ensure that only final data on cause of death are shared with the CRVS system – however the data may no longer be personally identifiable.

- **Data collated and sent to coordinator.** Integration at this point will provide aggregate data on maternal and perinatal deaths (with cause of death and associated ICD code); however, it will not include personal identifiers (but may still be presented by age and/or sex).

**Figure 4:** Typical data flow in an MPDSR system and types of data available for integration



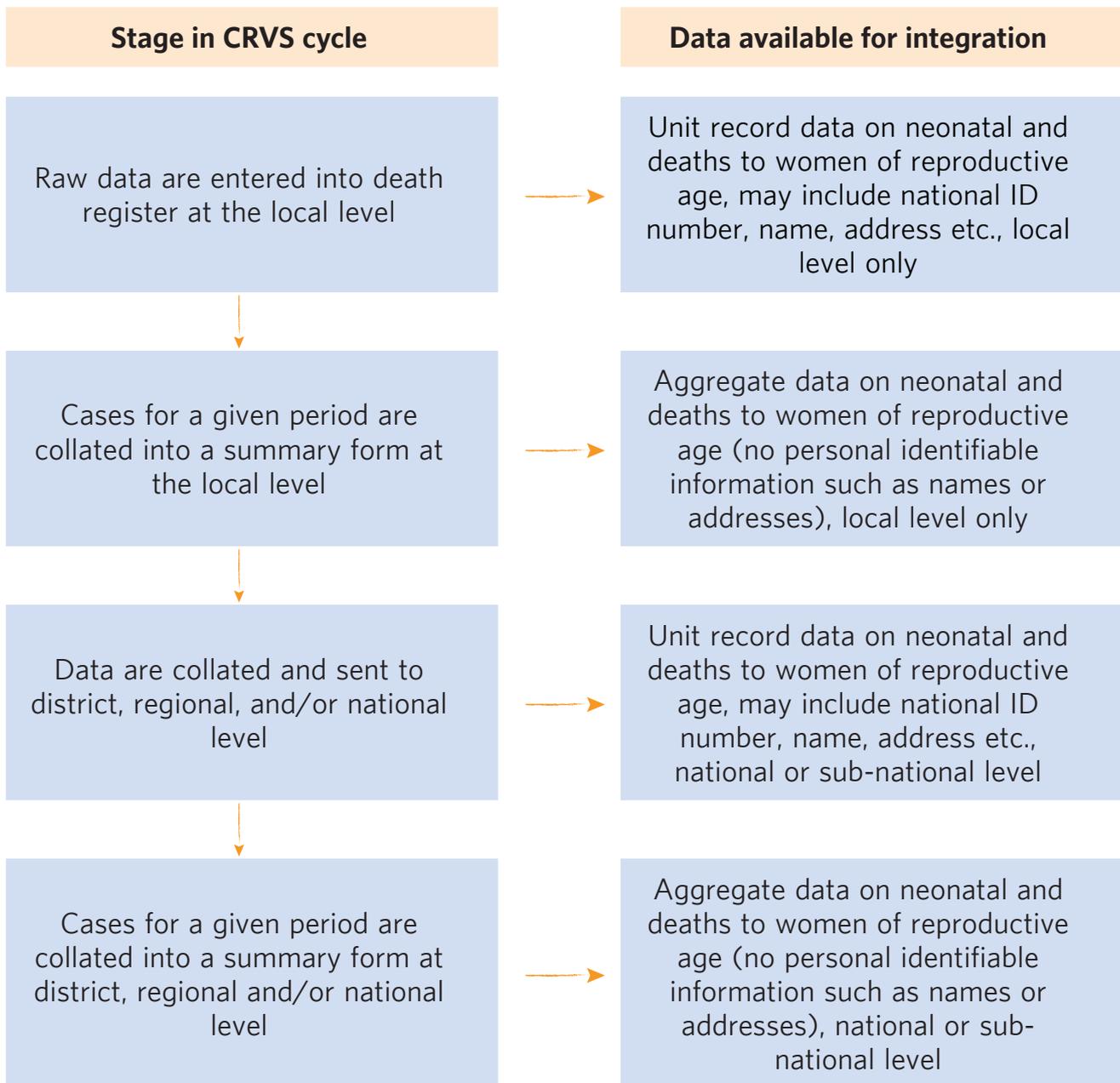
**Source:** Adapted from WHO, 2013 (4)

## Consideration for entry points within CRVS systems

Several types of integration can be done between the CRVS and MPDSR systems (Figure 5). If unit record data is being shared to increase coverage of deaths to women of reproductive age and neonates for perinatal death investigation for the MPDSR system, depending on the configuration of the CRVS system, data can be shared at the local, sub-national or national level. MPDSR systems that seek out community deaths could especially benefit from the sharing of information from the CRVS system to expand the number of deaths to investigate as coverage from MPDSR often primarily stemming from health facilities.

If aggregated deaths are shared from the CRVS system for either the purpose of data validation or cross-checking of counts, data can also be shared at the local, sub-national or national level. However, it should be cautioned that deaths are often registered locally in one district, but the death may have occurred in another district, particularly if the decedent sought health services from a larger health facility in the capital city, for example. This may make validation and cross-checking of counts problematic at the local level and should be considered when planning for integration of the two systems. Sharing information such as place of death may be useful for the purpose of integration for this reason. However, mortality and cause of death statistics, particularly maternal and perinatal mortality, should generally be tabulated by usual residence.

**Figure 5:** Typical data flow in a CRVS system and types of data available for integration



**Source:** Author's own

Based on the information gathered in sections 1A to 1E above, consider the following questions:

**1.F.1. Is unit-record linkage a possibility?**

1.F.1.1. If yes, can linkage occur at the local level? District level? Or would it need to occur at the national level?

1.F.1.2. If no, go to question 1.F.2.

## 1.F.2. Is data validation possible?

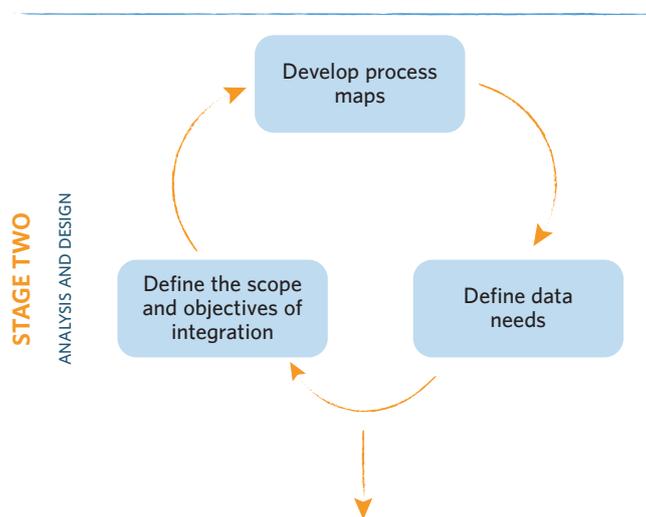
1.F.2.1. If yes, would validation occur at the local level? District level? Or would it need to occur at the national level?

1.F.2.2. If no, go to question 1.F.3.s

## 1.F.3. If unit-record linkage or validation is not possible, is it possible to cross-check basic aggregate counts of deaths?

1.F.3.1. If yes, would this occur at the local level? District level? Or would it need to occur at the national level?

## Stage two - analysis and design



Based on responses to questions in stage one and the conclusion summary from 1F, there should be a clearer understanding on what type of data integration is possible and at what level. The following steps will assist in further defining the scope of data integration and should be completed for all types, noting that for those countries looking at linking unit-record data, particular attention must be paid to issues of data privacy and security.

At the end of this stage, the following questions should have been answered:

- **What type of integration is being proposed (cross-checking aggregate data, validating aggregate data or linking unit-record data)?**
- **What is the purpose of data integration?**
- **What sectors will be involved in the data integration?**
- **Who will be responsible for overseeing the data integration?**
- **What data will be shared?**
- **In which stage in the process will integration occur and how will it occur?**

## Key resources

- *The Centre of Excellence for CRVS Systems has published a Compendium of Good Practices in Linking Civil Registration and Vital Statistics and Identity Management Systems*, available at:  
<https://crvssystems.ca/compendium-good-practices-linking-civil-registration-and-vital-statistics-crvs-and-identity>
- *Based on four country case studies, UNICEF developed a document on Good Practices in Integrating Birth Registration into Health Systems*, available at:  
[http://www.unicef.org/protection/Birth\\_Registration\\_Working\\_Paper\(2\).pdf](http://www.unicef.org/protection/Birth_Registration_Working_Paper(2).pdf)
- *Integrating community-based verbal autopsy (VA) into civil registration and vital statistics (CRVS): system-level considerations*, provides detailed guidance on the major system-level issues and a checklist of system-level considerations for integrating VA into CRVS systems. Download a copy at:  
<https://crvsgateway.info/file/17121/51>

## Considerations for humanitarian settings

Given the additional challenges and complexity of integration in humanitarian settings, it is recommended that any attempts at integration are implemented in health facilities first, before moving into more difficult settings (the community, rural/remote facilities, etc.).

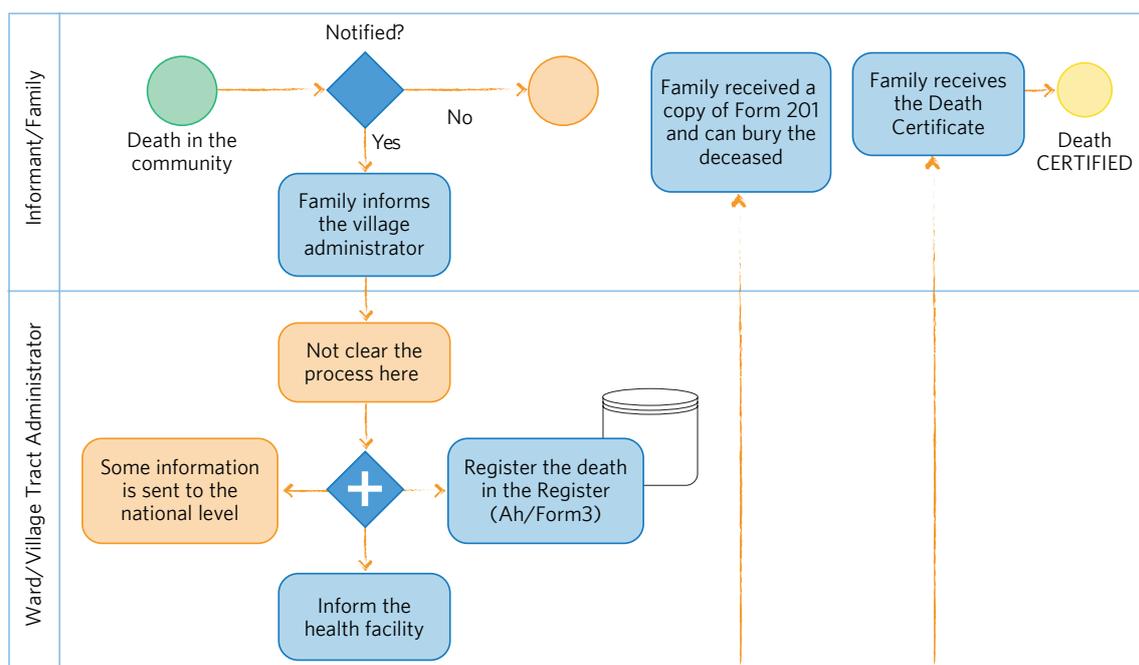
## 2.A. Develop business process maps for critical information pathways

Enterprise Architecture (EA) is a systems-science tool that produces various types of business process maps (51). It helps to describe, understand, analyse, compare and visualise the organisation, processes, workflows, and functionality of systems, and is a critical step in planning for data integration. There are three main types of business process maps that can be generated, each providing more detail than the previous (52).

**Relationship maps** graphically depict the main 'parts' of the CRVS and MPDSR systems, including stakeholders and sub-systems. They provide a detailed diagram of all the structural building blocks (government agencies, funding partners, suppliers, etc.) at various levels of the system to show relationships, connections, and linkages.

**Process maps** outline all major steps, processes and activities related to notifying, registering and certifying vital events in the CRVS system, including actors and agencies (28) (Figure 6). They provide the 'blueprints' of the system, highlighting critical steps in the process where maternal and perinatal deaths identified through MPDSR systems could be integrated.

**Figure 6:** Example process map for a death that occurred in the community

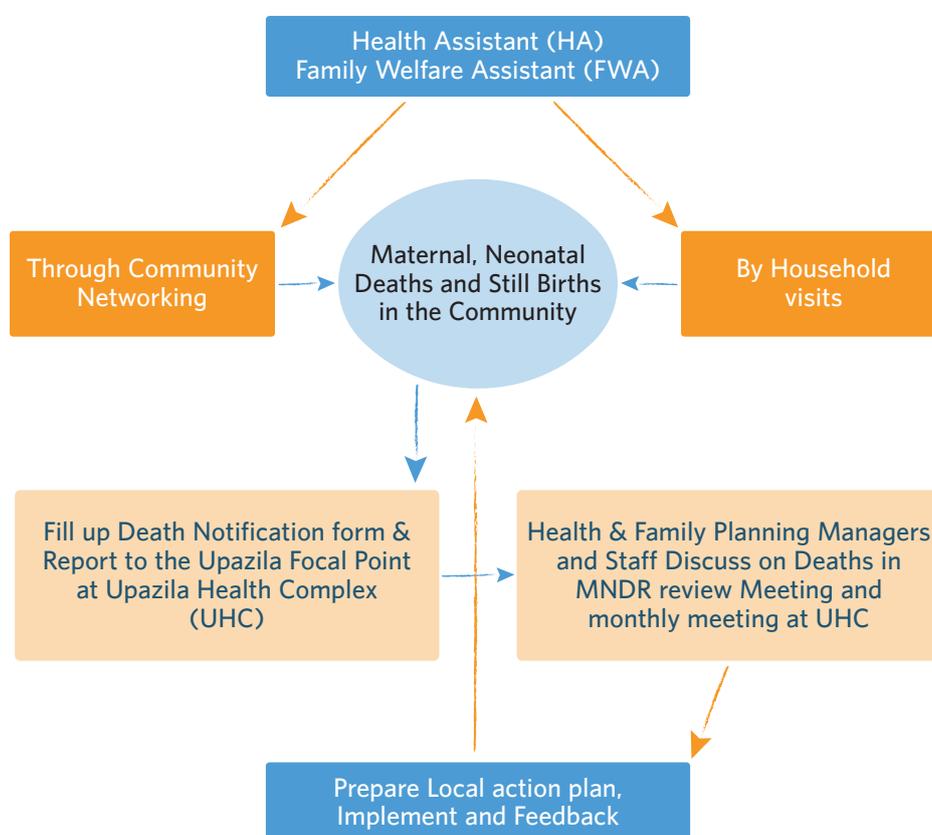


**Source:** de Savigny & Cobos Munoz, 2018 (51)

Process maps generally provide a higher-level overview of key steps in the information pathway (Figure 7). Process maps should be developed for both the CRVS and MPDSR systems and can include maps that show the systems as they currently operate ('as-is') and maps that show how the systems could operate with some improvements, including points of integration ('as-desired'). Important components to include in the process maps include identifying: **Who currently act as 'identifier-reporters'? that is, people who are informed or able to identify births and deaths in the community and relay information to the health system.** Notification can be carried out by various informants, including religious and political leaders, civil society organisations, those working in existing disease surveillance and response teams, community health workers, or those involved in vaccination programs (24). It is important that the process maps show how these identifier-reporters are formally connected to the health system, and subsequently to the CRVS system (6).

- **The mechanism for the transmission of information.** Will identifier-reporters report directly to the health facility, which has the potential to decrease the chance of duplicate reporting; or will they report to the lowest level of public health administration, which may be better suited when no individuals in specific facilities can be identified and the existing system is at the district level, but has the chance to increase duplications (6).
- **When in the process will the VA interview take place?** For countries that have unique identification (ID) or registry numbers as part of their CRVS system, it is important to ensure that notification occurs before a VA is scheduled. This helps to ensure the death already has an ID or registry number attached, thus reducing problems with data integration and the risk of double-counting (28).
- **Who is responsible for checking death logs** and records from the previous 24 hours? to identify all deaths among women of reproductive age (in facilities), which should then trigger a medical record review to identify possible maternal deaths (24).

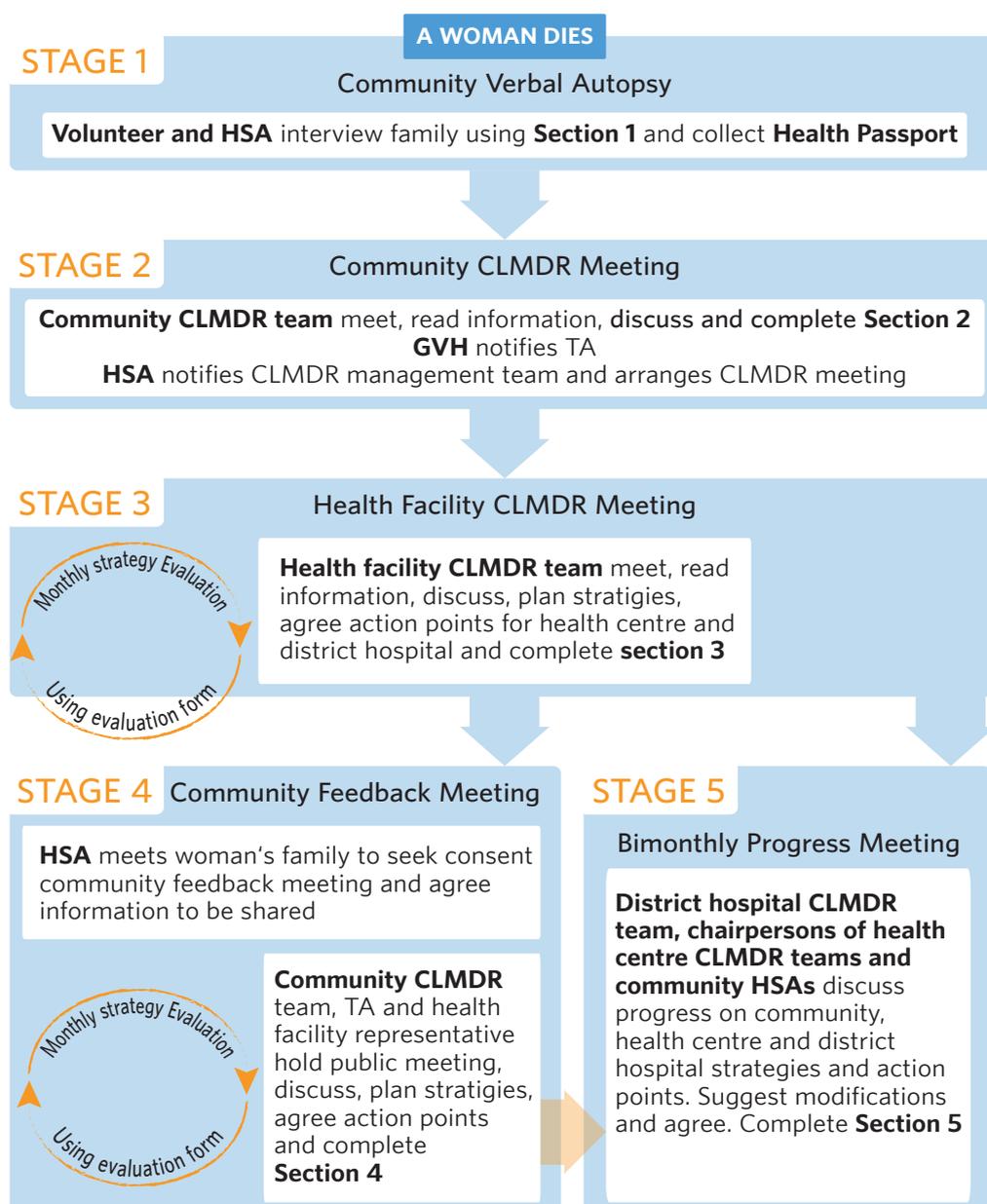
**Figure 7:** Simple process map showing community death notification in Bangladesh



**Source:** Biswas et al, 2014 (53)

**Flow chart maps** graphically depict the sequence of work activities used to produce a particular output within a process (Figure 8). This gives the most granular view of the work and information collected at various stages, including notification, registration, and the transfer of information between levels and agencies. By looking at the specific information being collected in a system (and the forms/processes used to collect such information), flow chart maps can highlight overlaps, duplication, wastage, etc., and show where data may be 'lost' through the system(s) (52).

**Figure 8:** Detailed flow chart map for a community-linked maternal death review



CLMDR, community-linked maternal death review; GVH, group village headman;  
 HSA, health surveillance assistant; TA, traditional authority

**Source:** Bayley et al, 2015 (21)

## Key resources

- More information about process mapping can be found at:  
<https://crvsgateway.info/CRVS-process-mapping-456>
- *Detailed guidance on how to apply business process mapping to CRVS systems is available through the CRVS Digitisation Guidebook, available online at:*  
<http://www.crvs-dgb.org/en/activities/analysis-and-design/2-define-the-crvs-business-architecture/>  
*Understanding CRVS systems: The importance of process mapping, available at:*  
<https://crvsgateway.info/file/16970/46>

## Considerations for humanitarian settings

Information management in humanitarian settings is vastly different, and as such, there are additional challenges in the registration of births and deaths and the establishment of mortality surveillance systems more generally. There are, for example, different barriers to registration for IPDs, to people from another country; protracted humanitarian emergencies also have a vastly different impact than temporary ones; while the restricted freedom of movement imposed on people living in refugee camps means their barriers (and opportunities) to registration are different from barriers to those living in the community. Given this, it may be necessary to develop process maps that show how a vital event is registered:

- For people living in a camp setting, those living in the community and those in informal settlements;
- For different population groups (within camps, in the community, and in informal settlements) such as refugees, asylum seekers and IDPs.

## Key resources

- *The Bali Process Civil Registration Assessment Toolkit provides a structured methodology for assessing legal and registration procedures, identifying any prohibitive laws, processes or requirements that may prevent refugees, asylum seekers, IPDs and persons of undetermined nationality from registering their vital events – with the goal of developing a national strategic plan to address these barriers, and measure improvements in registration. The toolkit can be downloaded from:*  
<https://www.baliprocess.net/UserFiles/baliprocess/File/Bali%20Process%20Civil%20Registration%20Assessment%20Toolkit%20FINAL.pdf>

**Before you continue:** Update the CRVS/MPDSR integration planning template

## 2.B. Define data needs for key stakeholders

Given the time and resources required for integrating data between systems, there must be a clear understanding of which data is required by each government agency – and if a use for the data cannot be identified, there may not be a need for sharing (6). This helps to limit the amount of data being shared between agencies, for which no defined use has been identified. For example, if the CRVS system only requires data from the MPDSR system to assist in generating a broad estimate of the magnitude of the problem, then linking simple counts of maternal and perinatal deaths should be sufficient (27). This may also mean that events captured by the MPDSR system may only need to be uploaded into the CRVS system at the end of each year, rather than on a continuous basis. If, however, the CRVS system needs to identify detailed causes, differentials, and determinants of death for routine monitoring and reporting, then linking unit-record data on outcomes from the full MPDSR review process may be necessary.

Key questions to consider:

- 2.B.1. Who are the potential users, and what are the potential uses of data from the MPDSR systems?** It is important to identify potential target audiences and understand their needs, so that high-value information products that are practical, flexible, relevant, responsive and timely can be developed and distributed (54). For example, while granular operational data are required for those working in the field, senior managers at the district or local level require data that has been synthesised and analysed for emerging themes.
- 2.B.2. Have either the CRVS or MPDSR system requested data from the other system before?** If so, what was it? How was the data shared?
- 2.B.3. What data are needed for civil registration purposes?** Is any of this data routinely collected as part of the MPDSR system?
- 2.B.4. Record the data needs of key stakeholders,** with a focus on data required for registering a death in the CRVS system, and data required for recording deaths in the MPDSR system.

## Key resources

- The *Social Statistics Data* section of UCLA Library (<https://guides.library.ucla.edu/data/definitions>) includes guidance on additional questions to ask when defining data needs and parameters, including:
  - Subjects – what do you want counted?
  - Time coverage – what time period(s) should the data cover?
  - Geographic coverage – what geographic area(s) should the data cover?
  - Cross-tabulation – do you want the data broken-down by characteristics like age, sex, or income?

**Before you continue:** Update the CRVS/MPDSR integration planning template

## 2.C. Defining the scope and objectives of data integration

Based on information from Stage 1 and sections 2.A. and 2.B., discuss the following questions with government counterparts:

**2.C.1. Briefly describe the purpose of data integration. What type of integration is being proposed (cross-checking aggregate data, validating aggregate data or unit-record data linkage)?**

**2.C.2. What is the legitimate and specific need of data integration?**

**2.C.3. What is the geographic location where integration will take place?**

**2.C.4. What sectors will be involved in data integration?**

**2.C.5. What is the name of the committee, sub-committee or task-force responsible for data integration?**

2.C.5.1. Who are the member agencies?

2.C.5.2. What are the terms of reference? Describe key components from the TORs, including: Purpose, Meeting frequency and membership composition, Roles and responsibilities and Role and choice of secretariat.

**2.C.6. Who will be responsible for overseeing data integration?**

**2.C.7. What information needs to be shared? This relates back to the previous section on data needs for key stakeholders. If there is a need for personally identifiable data to be shared to allow for unit-record linkage, then integration needs to occur earlier in the**

**process. However, sharing data earlier in the process increases the likelihood that the cause of death either has not been assigned or reviewed, and may be updated later in the process. If aggregate data on the total number of deaths (with or without cause) is required, then integration can occur later in the process, and potentially only every few months.**

## **2. C.8. At what stage in the process will integration occur and how will integration occur?**

- 2.C.8.1.** Are there opportunities to automate the reporting/notification of deaths, so that both the CRVS and MPDSR systems receive real-time data on deaths? This may include the establishment of registry offices in hospitals and major health facilities, or providing health facilities with direct access to shared registry databases. Note that while this will provide more complete data on deaths by (at a minimum) age and sex; it may not be able to accurately identify maternal deaths or provide data on cause of death or outcomes from the MPDSR review process.
- 2.C.8.2.** Are there opportunities to link or cross-check maternal death databases (if they exist) with civil registry databases? In Oman, for example, when the MPDSR system identifies a death and upon cross-checking with the CRVS system finds that it has not been registered, a 'placeholder' death is recorded in the CRVS system. This placeholder helps to improve the completeness of mortality statistics; however the death event itself is not officially registered until all legal requirements regarding the registration of a death are met. While such integration or cross-checking will ensure that only data on maternal and perinatal deaths are shared with the CRVS system, the data may take longer to receive and has the potential to include duplicates (especially for systems that do not have unique ID numbers for each death).

**Before you continue:** Update the CRVS/MPDSR integration planning template

## Stage three - implementation planning



As implementation will depend on country context and the status of CRVS and MPDSR systems, along with the proposed design of data integration – this section does not attempt to provide specific recommendations or action steps that each country should follow. Rather, it highlights common issues and challenges countries may face during implementation, which should be taken into consideration by the country office during planning. Before moving through implementation issues, country offices should review with government stakeholders the four important lessons from broader programs of work that have taken place in linking civil registration with other systems and agencies:

1. **“Think big, but start small and grow slowly”** (20). Previous country experiences have demonstrated the critical importance of starting simply and taking a phased approach (6, 38, 55). This includes starting with a situational analysis and building on existing CRVS and MPDSR systems and processes. Focussing efforts on government-controlled facilities in urban areas first, where the likelihood of success is higher, is encouraged – before moving into less-advanced settings (deaths in communities/at home, rural areas, humanitarian/refugee camps, private facilities, etc.) (6). Taking a phased approach also includes starting by linking basic data on the number of maternal and perinatal deaths first before moving to link more complex data on cause of death, verbal and social autopsy results and outcomes from the full MPDSR review process (24).
2. **Promote local ownership of the process.** Local ownership and leadership are critical (19). Key stakeholders from both the CRVS and MPDSR systems need to lead the process from start to finish and

provide leadership at all levels. This helps to ensure the sustainability of data integration processes and that the right data are being shared with the right agencies at the right time. If, for example, midwives provide the majority of care and support, particularly for births occurring in the community, they should play a key role in information management and leadership (18).

3. **Systems-strengthening is needed as part of the overall approach** (56). Key findings from the 'Compendium of good practices in linking CRVS and ID systems' (40), should be considered; for example, the need for a conducive legal framework, effective institutional arrangements, and foundational level of administrative system maturity. The ability to share data between agencies generally requires developing a data privacy and protection framework to ensure the security and confidentiality of data (15, 40). As part of integration, the continuous monitoring of issues is required, along with the development of strategies to address issues – particularly at the beginning of the process (28). Implementing systems of data quality assurance at each stage will also help ensure the validity of data once linked. Any frameworks, policies, or procedures developed should be designed to strengthen the entire CRVS and/or MPDSR systems, both to ensure sustainability and prevent the creation of 'siloes' information systems.
4. **Technology is an enabler not a 'fixer'**. While digitisation can dramatically increase data linking efficiency and standardise how events are defined, configured, created, stored, shared and processed (19, 56), a lack of detail in records, particularly those surrounding maternal and perinatal deaths, is still an issue with many electronic systems (57). Experience from strengthening CRVS systems has shown that countries with successful technological programs all had high rates of registration coverage before starting digitisation, including the establishment of an initial database for storing digital records (15, 40). Technology is most effective when integrated within established work processes and work systems (54, 58). It also requires a reliable electricity source, Internet connectivity and sufficient trained workforce to operate the system, along with ongoing resources for maintenance (56).

### 3.A. Advocacy

Advocacy can be used to raise awareness of the importance of CRVS and MPDSR systems and help inform government agencies and civil society partners of the benefits of pursuing a specific intervention or policy direction – such as the need for integration between the two systems. Stakeholders

involved in the two systems may have different responsibilities, perspectives and agendas. Government agencies are also likely to have multiple budget demands and may require convincing of the benefits of investing in integration between CRVS and MPDSR systems, particularly if financial and human resources will be required. Advocacy aimed at CRVS and MPDSR integration is necessary to help fill gaps in knowledge, modify attitudes on the importance of shared data for improved quality of care and evidence-based decision making, and to change current practices (59). Advocacy works best when information is used in a deliberate and strategic way to share a common message – ensuring that stakeholders are both informed on the issue and asked to be part of the solution (3).

Part of advocacy efforts may include the country office supporting the development of a business case to justify the benefits of integrating CRVS and MPDSR systems, particularly for government agencies that have not worked together closely before (a template is provided in **Annex 2**). Business cases can also be presented to partner organisations when requesting additional resources for design and implementation. The business case should outline the substantial advantages of integrating CRVS and MPDSR systems, including strengthening the notification and registration of maternal and perinatal deaths, increasing the completeness of mortality statistics from the CRVS system, and improved data for evidence-based decision making.

### Key resources

- Guidance on how to develop a business case for investing in civil registration is available at:  
<https://crvsgateway.info/file/16919/95>
- A range of advocacy materials are available through the UN's Economic Commission for Asia and the Pacific website on CRVS:  
<https://getinthepicture.org/resources>
- The CRVS Digitisation Guidebook is an online resource that provides step-by-step guidance for countries to plan, analyse, design and implement digital systems and automated processes for CRVS. It contains detailed information about how to use the EA methodology in CRVS systems and is available at:  
<http://www.crvs-dgb.org/en/methodology/>

### 3.B. Human resource issues

It is important to understand current human resource availability and needs in the CRVS and MPDSR systems (28), taking into consideration the significant human resource challenges in humanitarian settings (along with the number of additional agencies and partners involved). Data integration may require new functions to be added to existing roles, along with training and supervision – particularly during initial stages of implementation. For example, who will be responsible for ensuring that data are being shared between agencies, or for checking for possible duplication in linked records? Country offices may need to support updating job descriptions, and development of training plans and materials for these new functions.

### 3.C. Financing issues

As there is limited experience in integrating data from CRVS and MPDSR systems, it is difficult to estimate both start-up and ongoing costs. However, financial resources will likely be required for:

- Supporting the coordination mechanism. Funds may be required for refreshments during any associated committee or taskforce meetings and for travel costs for members (particularly those travelling to/from conflict zones in humanitarian settings). These costs should reduce as data integration becomes embedded in routine processes.
- The development and implementation of any associated training plans (including development and production of materials, costs for facilitators, workshop costs, etc.).
- IT support, particularly if databases need to be updated or modified as part of integration.

Country Office support to understand financing needs and develop a budget is a key to successful and sustainable integration.

### 3.D. Infrastructure and information technology systems

Through process and information mapping, existing gaps in infrastructure and IT in the CRVS and MPDSR systems should be well known and understood. If integration will occur directly, perhaps by a shared IT platform, then it is important to ensure there are enough computer terminals, as well as supporting infrastructure such as power supply and Internet connectivity. It is also important that software packages are designed with a clear understanding

of key fields to capture and how they will come together in the system. If integration will occur through the sharing of paper-based forms, it is equally important to ensure enough forms have been produced and distributed to the relevant agencies/facilities. For both digital and paper-based integration and sharing, it is vital that roles and responsibilities are clearly stated, particularly around who will collect any additional information required and enter it into the system or form.

Increasingly, CRVS and MPDSR systems will be digital rather than paper-based from the point of data capture, including the use of both mobile data and wireless network capacity (28). It is important that data integration is designed with this in mind to ensure any new processes implemented will not become obsolete in a short timeframe. The flow of data should be designed and managed from an enterprise architecture (EA) perspective – EA is the industry standard for designing interoperability in information and communication applications (60). One of the biggest challenges in interoperability (the ability of different systems to 'talk' to each other) relates to how raw data are coded in the system. If, for example, different systems use different geocode references for location data, then linking data based on residence will be difficult. Similarly, if one system codes 'male' as '0' and female as '1'; while another codes them as the reverse, integration will be equally difficult. Supporting agencies to harmonize variable categories and definitions is one small, but straightforward way to work towards successful integration.

E-governance, data security, confidentiality and data encryption issues all need to be addressed (60). Skills for these functions are often not available in-country, requiring the inclusion of dedicated human resources in IT. In areas where mobile and wireless networks are not reliable, or for humanitarian settings more generally, data integration may require someone from the civil registry office going to the relevant health facilities and downloading relevant data manually through a USB connection, or taking copies of paper-based forms.

### Key resources

- More information about defining data requirements from an IT perspective is available through the Office of the National Coordination for Health Information Technology:  
<https://www.healthit.gov/playbook/pddq-framework/data-operations/data-requirements-definition/>
- The CRVS Digitisation Guidebook is an online resource that provides step-by-step guidance for countries to plan, analyse, design and implement digital systems and automated processes for CRVS. It contains detailed information about how to use the EA methodology in CRVS systems and is available at:  
<http://www.crvs-dgb.org/en/methodology/>

### 3.E. Quality assurance

The integration of data from CRVS and MPDSR systems is a complex undertaking, and while potential benefits are great, success will rely on a variety of stakeholders, each with their own incentives and impediments to performing their particular role in the overall process (28). Integration is also reliant on communication mechanisms, IT processes and infrastructure used to facilitate data flow, and the eventual use of the information for better statistics on maternal and perinatal health. Critical to the sustainability and effectiveness of data integration is the need to introduce changes in a phased manner, with structured monitoring and evaluation (M&E) processes leading to adaptations and continuous improvements (12). M&E will be primarily carried-out at the national level, however developing indicators that can assess improvements at the district (or facility) level is also important (4), as is the development of specific indicators to monitor partner activities, particularly in humanitarian settings (49). Country offices should support the development of M&E to ensure both systems can be as mutually reinforcing as possible.

Periodic review should evaluate (4, 28):

- How **efficient** the system is, that is, if integration is happening as it should. This could include an assessment of key processes, including the number of districts or facilities that are sharing data, the number of deaths identified in one system but not the other, and the time taken from an event being identified/ notified to its inclusion in both systems.
- The **quality** of data being entered in both systems. Quality can be assessed at various stages – at the point of collection, the quality of microdata can be assessed; following this, the accuracy and

completeness of individual records can be assessed; while aggregate data can be assessed for accuracy and plausibility. Overall data quality can also be assessed by independent research institutes and academia.

- How information is being **used** and by whom. This is an important metric to assess if the data being linked were actually what was needed by the various stakeholders, or if additional data are still required to make the information useable and useful.
- Identified **issues and barriers** during integration, particularly if one or more steps during the process are not functioning as expected. Where possible, an audit system for logging events and issues should be developed, ensuring that issues are identified as they occur and resolved as soon as possible. Referring to the original business process maps developed (as part of stage 2. B) can be a useful method to help identify and resolve issues and barriers.

#### Key resources

- WHO's Maternal Death Surveillance and Response Technical Guidance includes a chapter on establishing monitoring and evaluation frameworks with example indicators, which could be adapted for use in integration projects. The document is available at:  
[https://apps.who.int/iris/bitstream/handle/10665/87340/9789241506083\\_eng.pdf](https://apps.who.int/iris/bitstream/handle/10665/87340/9789241506083_eng.pdf)

### 3.F. Additional considerations for linking unit-record data

The two main methods used in unit-record linkage – deterministic and probabilistic – attempt to match a given set of 'identifiers' between two records, such as name, date of birth or death, sex, usual address, etc.. Overall, information-rich scenarios that have direct or unique identifiers available for matching are best suited to deterministic methods, which are easier to implement and interpret. In information-poor scenarios, where direct identifiers are not available or the data is of poor quality, probabilistic methods tend to outperform deterministic ones, making them the more suitable choice (2). Regardless of the method chosen, there are five important factors to consider before implementing unit-record data linkage (32):

1. **Feasibility.** The feasibility of data linkage is largely dependent on data quality, including the quantity and quality of potentially identifiable information available from different datasets. Different identifiers

used in linkage can be more or less informative, depending on their discriminatory power and the number of unique values available. Overall, matches on rarely occurring values are less likely to occur by chance, increasing the probability that a 'true' match has been found between two records.

2. **The original purpose of collecting the data**, including if any of the terms of collection prohibit future linkage. Quite apart from the technical ability of the data to be linked, this considers possible ethical and legal restrictions.
3. **Data ownership, regulatory requirements and limitations over data use**. A data governance plan should outline issues such as:
  - a. Who owns the data, who granted approval for the data to be used, and who can grant access to the data.
  - b. What regulatory requirements the data are subject to and what is 'acceptable use'.
  - c. Where the data will reside.
  - d. When various stakeholders will be brought into the process.
  - e. How data use approvals will be granted and how data will be managed and secured.
  - f. Why the data are to be linked, including the overarching purpose and goal of linkage.
4. **Data sharing and security concerns**. Adequate steps must be taken to protect personally identifiable information, including the option of engaging with a third-party to act as an independent data manager.
5. **Privacy protection during linkage**. Growing concerns over data privacy and security at the global level have made traditional methods of record linkage challenging, as the primary goal of linkage is to identify the real-world person represented by the data so their 'entity' can be linked with other data instances.

## Key resources

- Linking data for health services research, developed by the Agency for Healthcare Research and Quality, is a detailed resource that defines the requirements for record linkage, and describes the strengths and weaknesses of different methods. It also serves as an instructional guide for those designing record linkage projects and includes practical examples that can be used during the project planning and implementation phases, including project planning and execution checklists. The document is available to download at:

<https://www.ncbi.nlm.nih.gov/books/NBK253313/>

## Next steps and recommendations

A roadmap is presented below that lists the sequence and main steps recommended for Country Offices to support governments when implementing data integration. Steps may be added or deleted as necessary to adapt the roadmap to the specific country situation.

1. **Support identification of a lead government agency and local 'champion'.** To start the process and form a coordination mechanism, it is generally necessary for the government to first nominate an agency that can lead the process and can identify and invite other stakeholders to participate. In many settings, the initial push for this stage has come from one government agency, or one or more local 'champions' who are working in the area of CRVS and/or MPDSR, and are eager to improve the availability and quality of data on maternal and perinatal deaths.
2. **Make a case to government and/or relevant agencies.** In order for integration to succeed, there must be broader awareness and acceptance of the need to use multiple data sources for monitoring maternal and perinatal deaths. As such, the development of advocacy materials may be required, which outline the benefits of integration for strengthening both CRVS and MPDSR systems. The lead government agency may also want to develop a business case that outlines the substantial advantages of integrating CRVS and MPDSR systems, including strengthening the notification and registration of maternal and perinatal deaths, increasing the completeness of mortality statistics from the CRVS system and improved data for better evidence-based decision making.
3. **Support the formation of a coordination mechanism.** The mechanism (committee, sub-committee, taskforce, etc.) must have strong representation from all the agencies involved in both CRVS and MPDSR systems, and from humanitarian settings (where applicable). While support from senior government officials is crucial for the overall success of data integration, the actual process of planning and implementation is best carried out by those responsible for the day-to-day activities in the CRVS and MPDSR systems.
4. **Support completion of a simple 'starter'/pilot project (30).** For agencies that have no or very little prior working connections, it may be a good idea to start with a simple project, such as comparing the number of maternal and perinatal deaths captured in both systems over a recent period. This project should be the responsibility of the coordination mechanism with support from the country office as needed.

5. **Support government counterparts to complete the stages outlined in this guidance.** The planning template provided in Annex 1 should be used to keep a record of important information and any key decisions made on data integration.
6. **Review the principles of integrating data from CRVS and MPDSR systems,** based on country experiences of linking CRVS systems with other systems and agencies (see Stage three – implementation planning).
7. **Support development of a customised methodology for integration.** The planning template will contain much of the information required for this document, particularly for projects looking to cross-check or validate aggregate data. Additional expertise will likely be required for those looking to implement unit-record data linkage – with many countries establishing partnerships with academic institutions to provide technical assistance at this stage.<sup>2</sup> Support needed partnerships and reach out to the wider UNFPA global network with questions or for suggestions.
8. **Support the convening of the coordination mechanism to conduct a results meeting.** This meeting is particularly important if there have been several different sub-groups working on different stages and steps in the guidance. The results meeting provides space for all sub-groups to present their findings and arrive at a set of agreed recommendations on the scope of the integration. Support from the Country Office could be financial, secretarial, technical or all of the above.
9. **Support Implementation.** Specific actions and the way the integration is implemented will vary among countries. As part of implementation and improvement, it is important to help the government monitor progress by periodically assessing how well integration and sharing are working and if there are any bottlenecks or other issues/ challenges preventing data from being shared between systems. Based on available literature and country experiences, overall recommendations for implementation include:
  - Implementation should be phased – as a starting point, look to share data on all deaths captured by the MPDSR system. Ideally, this would be unit record data; however summary counts of deaths by age and sex would also help improve completeness of data in the CRVS system. Once processes are in place, then look

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2. The Australian Institute of Health and Welfare, for example, have partnered with the University of New South Wales for their maternal mortality project, and an example of their data linkage methodology is available at: <https://www.aihw.gov.au/reports/mothers-babies/maternal-mortality-data-linkage-methodology/contents/table-of-contents>

to share data on deaths that have been confirmed as maternal or perinatal (requiring accurate cause of death data that have been coded and through the review process) (27).

- Aim to link all relevant data collected on maternal and perinatal deaths that occur in health facilities (as required for registration); however for deaths that occur in the community, 'integration' may be limited to sharing the number of suspected maternal and perinatal deaths on a routine basis (6).
- In **humanitarian settings** the following recommendations also apply:
  - i. Implementation should be phased and start with government-operated health facilities (likely in urban areas), before moving into more difficult settings (rural/remote facilities, non-government facilities, the community, etc.)
  - ii. Implementation needs to be adapted to the humanitarian setting - integration during the acute phase of emergencies will likely be limited to counts of death, while integration during prolonged emergencies can look to include more detailed data (including cause of death). Data integration will also be different depending on the type of humanitarian setting - camp, community or informal settlements.

# Annex 1.

## CRVS/MPDSR data integration planning template

It is recommended that Country Offices support and encourage agencies to complete, as much as they can, this planning template while working through the stages outlined in this guidance. Do not worry if the document is incomplete or if all questions cannot be answered at the start, as the template may need to be revised or updated with users' progress. Once complete and users have worked through the stages in the guidance – this planning template can be used as a summary of key decisions made to assist moving forward to next steps.

### Preparation

*Complete the table below*

<b>Country (or region):</b>	
<b>Describe the country context:</b>	Describe access to sites, security, internet coverage, literacy, political stability, etc.
<b>1.A Active humanitarian emergencies (if applicable):</b>	Describe access to sites, security, internet coverage, literacy, political stability, etc. <b>1.A.2.</b> What proportion of refugees, asylum seekers and IDPs are living in host-communities? What proportion living in camp settings? What proportion living in informal settings?

<b>1.B. Legislative framework:</b>	<b>1.B.1.</b> Is the level of data protection afforded by all government agencies equal?
	<b>1.B.2.</b> Have any data protection rules or privacy requirements applicable to the data been satisfied prior to integration?
	<b>1.B.3.</b> Is there legislation that prohibits data sharing between government agencies?
<b>1.C. Coordination mechanism:</b>	<b>1.C.1.</b> Who are the key stakeholders in the CRVS and MPDSR systems?
	<b>1.C.2.</b> Are there existing coordination mechanisms that could be utilized?
	<b>1.C.3.</b> Are there champions from each of the main agencies who could help to advocate for the development of coordination mechanisms?
<b>1.D. CRVS system status:</b>	<b>1.D.1</b> CRVS system overview:
	<b>1.D.1.1</b> What was the WHO Rapid assessment overall score and system classification for the country (if applicable)?
	<b>1.D.1.2.</b> What areas of the rapid assessment (as they relate to MPDSR systems) did the country score lowest in?
	<b>1.D.1.3</b> Is the CRVS system primarily paper-based or electronic?
	<b>1.D.1.4.</b> For systems that are electronic, at what point during data collection is data entered into the electronic system (i.e. at the health facility level, regional level, national level, etc.)?
	<b>1.D.1.5.</b> Do other agencies have access to the CRVS system (if electronic)?

**1.D. CRVS  
system status:**

**1.D.2.** What are the legal basis and resources for civil registration? (Note: sections 1.D.2, 1.D.3, 1.D.4, 1.D.5, and 1.D.6 correspond to questions which are from the WHO comprehensive assessment of CRVS. The question numbers below correspond to the question numbers in the WHO Comprehensive assessment tool)

**WHO Comprehensive assessment question numbers:**

- A1.1** Does the country have a law defining a civil registration system?
- A1.3** Does the law clearly state that birth and death registrations are compulsory?
- A1.7** Does the birth registration law give clear and unambiguous definitions to be used for: live birth; and foetal death or stillbirth?
- A1.8** Are these definitions aligned with international standards?
- A1.11** Is there a law or regulation requiring hospitals and health facilities to report births and deaths? If so, to what authorities do they report such births and deaths?
- A1.12** If yes, to what authorities do they report births and deaths?
- A1.20** Does the law clearly designate the functions, duties and responsibilities of each government department involved?
- A1.24** Is the population covered by civil registration laws clearly defined? Is it, for example: the entire population living in the country; only citizens living in the country; some other subsets of the population?
- A1.25** What does the law require in relation to registering births and deaths of citizens living abroad?
- A1.26** What does the law require in relation to registration of births and deaths of: foreign nationals living in the country; nomadic or displaced populations; refugees and asylum seekers?

## 1.D. CRVS system status:

**1.D.3.** Describe current registration practices, coverage, and completeness

WHO Comprehensive assessment question numbers:

- B1.5** What are the current communication mechanisms between the civil registration authority and others involved in the collection and production of vital statistics?
- B1.6** Are there any areas where the responsibilities for specific functions overlap or are unclear?
- B1.11** Are there some vital events that cannot be registered through the normal system?
- B1.12** Are the same data on births and deaths collected across the country and at every level of the system (including state or provincial, national or local levels)?
- B1.14** Is cause of death included on the death registration form?
- B1.15** If not, is information about the cause of death collected at the same time as the death is registered but using a different form? Also discuss what happens with coronial cases and deaths from suspected non-natural causes
- B1.17** How is medical information on births and deaths exchanged among the different government agencies involved?
- B1.18** Is this process currently working well or does it need improvement?
- B1.23** Are computers used at any stage of the birth and death registration process?
- B1.24** Are computers used for any or all of data: compilation; transmission; validation; storage?
- B1.28** What procedures for checking completeness and consistency of information are carried out at central and other levels?
- B3.7** What subpopulations are most likely to be undercounted in vital registration? (Note: undercounting may be different for births and deaths).

**1.D. CRVS  
system status:**

**1.D.4.** Describe current practices around death certification and cause of death

**WHO Comprehensive assessment question numbers:**

**C1.1** How many registered deaths (as a percentage) have a medically certified cause of death?

**C1.4** Are ICD-compliant practices used for death certification in the country?

**C1.5** Is the standard international form of medical certificate of cause of death used for: all deaths; only deaths occurring in hospitals not for those taken place outside hospitals; only deaths occurring in some specific hospitals, such as university or regional hospitals; other deaths?

**C1.7** Do doctors know how to correctly complete the death certificate, including the causal sequence and the underlying cause?

**C3.3** Is the same cause-of-death form used for deaths in and outside hospital?

**C3.4** If a different form is used for deaths outside hospital, what information is recorded about the cause of death?

**C4.4** Does the death certificate state whether a woman was pregnant, or had recently been pregnant?

**C4.5** Are maternal deaths reviewed separately from other deaths?

**C4.6** Are perinatal deaths monitored using a special form, as recommended by the WHO?

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**1.D.5.** Describe current ICD mortality coding practices

**WHO Comprehensive assessment question numbers:**

**D1.11** Is cause-of-death coding done from a copy of the original death certificate or from a transcribed list provided by the civil registration office, or from some other summary document?

**D1.12** Is all the information on the death certificate coded, or only the presumed underlying cause of death?

**1.D. CRVS  
system status:**

**1.D.6** Describe data access, use, and quality checks

**WHO Comprehensive assessment question numbers:**

**E1.8** Are fertility rates derived from civil registration and vital statistics compared with rates derived from other sources?

**E1.9** Are mortality rates derived from civil registration and vital statistics compared with rates derived from other sources?

**1.E. MPDSR  
system status:**

**1.E.1** Is there a national policy to notify and review all maternal and perinatal deaths?

**1.E.1.1** Is there a national MPDSR plan?

**1.E.2.** What components of MPDSR are already in place and where?

**1.E.2.1.** What are the aims and purpose of MPDRs?

**1.E.2.2.** Who are the actors engaged in the process?

**1.E.2.3.** How are they carried out?

**1.E.2.4.** What information is recorded on each death?

**1.E.3.** What is the scale of coverage of the system?

**1.E.4.** What proportion of deaths is estimated to be notified from health facilities and from the community?

**1.E.5.** Where are deaths identified from as part of the system?

**1.E. MPDSR  
system status:**

- 1.E.6.** Is the MPDSR system primarily paper-based or electronic?
- 
- 1.E.7.** For systems that are electronic, at what point during data collection is data entered into the electronic system (i.e. at the health facility level, regional level or national level)?
- 
- 1.E.8.** Do other agencies have access to the MPDSR system (if electronic)?
- 
- 1.E.9.** What is the scale of the review process?
- 
- 1.E.10.** Is there a national committee for maternal and perinatal deaths? Is there a sub-national committee?
- 1.E.10.1.** How often do committees meet?
- 1.E.10.2.** What is the membership composition of the committees?
- 
- 1.E.11.** If more than one system that reports maternal and perinatal deaths is currently in place, how do these systems interact?
- 
- 1.E.12.** Is there a system of integrated disease surveillance and response (IDSR) in place and, if so, does it report the number of maternal deaths?

**1.1 Summary:**

- 1.F.1.** Is unit-record linkage a possibility?
- 1.F.1.1** If yes, can linkage occur at the local level? District level? Or would it need to occur at the national level?
- 1.F.1.2** If no, go to question 1.F.2
- 
- 1.F.2.** Is data validation possible?
- 1.F.2.1.** If yes, would validation occur at the local level? District level? Or would it need to occur at the national level?
- 1.F.2.2** If no, go to question 1.F.3
- 
- 1.F.3.** If unit record linkage or validation is not possible, is it possible to cross-check basic aggregate counts of deaths?
- 1.F.3.1.** If yes, would this occur at the local level? District level? Or would it need to occur at the national level?

## Analysis and design

Complete the table below

<b>2.A. Business process maps:</b>	Insert any maps developed
<b>2.B. Data needs:</b>	<b>2.B.1.</b> Who are the potential users, and what are the potential uses of data from MPDSR systems?
	<b>2.B.2.</b> Have either the CRVS or MPDSR systems requested data from other systems before?
	<b>2.B.3.</b> What data are needed for civil registration purposes?
	<b>2.B.4.</b> Record the data needs of key stakeholders
<b>2.C. Define the scope and objectives of data integration:</b>	<b>2.C.1.</b> Briefly describe the scope and purpose of data integration
	<b>2.C.2.</b> What is the legitimate and specific need of the data?
	<b>2.C.3.</b> What is the geographic location where integration will take place?
	<b>2.C.4.</b> What sectors will be involved in data integration?
	<b>2.C.5.</b> What is the name of the committee, sub-committee, or task-force responsible for data integration?
	<b>2.C.5.1.</b> Who are the member agencies?
	<b>2.C.5.2.</b> What are the terms of reference - Describe key components from the TORs, including: <ul style="list-style-type: none"> <li>• Purpose</li> <li>• Meeting frequency and membership composition</li> <li>• Roles and responsibilities</li> <li>• Role and choice of secretariat</li> </ul> <b>2.C.6.</b> Who will be responsible for overseeing data integration?  <b>2.C.7.</b> What information needs to be shared?

**2.C. Define the scope and objectives of data integration:**

**2.C.8.** at Which stage in the process will integration occur and how will integration occur?

**2.C.8.1.** Are there opportunities to automate the reporting/notification of deaths, so that both the CRVS and MPDSR systems receive real-time data on deaths?

**2.C.8.2.** Are there opportunities to link or cross-check maternal death databases (if they exist) with civil registry databases?

### Implementation planning

Complete the table below

<b>3.A. Advocacy</b>	Include any important information or decisions made about the need for advocacy
<b>3.B. Human resources</b>	Include any important information or decisions about human resources available for data integration
<b>3.C. Finance</b>	Include any important information or decisions about the finances available for data integration
<b>3.D. Infrastructure and information technology</b>	Include any important information or decisions about the infrastructure and information technology available or required for data integration
<b>3.E. Quality assurance</b>	<p>Include any important information or decisions about monitoring and evaluation. Some things to consider are:</p> <ol style="list-style-type: none"> <li>1. How efficient the system is, that is, if integration is happening as it should.</li> <li>2. The quality of data being entered in both systems.</li> <li>3. Identified issues and barriers during integration.</li> </ol>

# Annex 2.

## Business case template

**This template provides the basic structure of a business case, and main points that should be included under each section, including sample text where applicable. Text displayed in square brackets with yellow highlight needs to be updated with country information/data, while red/italicised text are instructions and need to be deleted once read.**

Developing mutually reinforcing CRVS and MPDSR systems in [**country**]

Business case

### Executive summary

**The executive summary is the most important part of the business case and might be the only section that most people read. Remember to keep the summary short and provide a high-level overview of the problem, options and recommendation(s).**

### Introduction

**The introduction should (in simple, non-technical language) explain what the business case is about and provide any background information necessary to help readers understand the scale of the problem and importance of addressing it. Sample text is provided below, which can be updated or replaced entirely.**

A civil registration system is the "...continuous, permanent, compulsory and universal recording of the occurrence and characteristics of vital events pertaining to the population, as provided through decree or regulation in accordance with the legal requirements in each country".<sup>3</sup> Vital events, including births, deaths, marriages and divorces, are translated into statistics through a country's vital statistics system. A civil registration and vital statistics (CRVS) system, in turn, refers to the production, dissemination and use of statistics on vital events as captured through civil registration. The recording of live births, and deaths by age – basic functions of any civil registration system – allows for the identification of potential maternal and perinatal deaths, and

<sup>3</sup> United Nations' Principles and Recommendations for a Vital Statistics System (paragraph 279, page 65)

the generation of key indicators such as the maternal mortality ratio (MMR), perinatal mortality rate (PNMR) and neonatal mortality rate (NMR).

Maternal and perinatal death surveillance and response (MPDSR) systems refer to the notification, review, analysis, and response to maternal and perinatal deaths, and are a form of continuous surveillance linking health information systems and quality of care improvement processes from local to national levels. They were developed to help avoid preventable maternal and perinatal mortality and morbidity through the identification of critical failures in the care pathway and taking action to prevent similar deaths occurring in the future. MPDSR draws on the health management information system (HMIS) of a country and can be strengthened by linkages with the civil registration and vital statistics (CRVS) system.

Many maternal and perinatal deaths go unrecorded or misclassified because the system for CRVS is weak. Accurate maternal and newborn mortality ratios require robust CRVS systems that record every death and cause of death correctly. Accurate and comprehensive information about the causes of women's deaths can be difficult to acquire and therefore difficult to label as maternal deaths. An effective MPDSR system informs on the main causes of maternal and perinatal deaths and produces accurate and complete estimates of maternal and perinatal mortality, providing robust and consistent data for monitoring trends in mortality and related medical and systemic causes of death. Where reliable CRVS systems do not exist, MPDSR can provide a cornerstone of a new system, and contribute significantly to a country's 'culture of accountability' and evidence-based decision and policy making by connecting actions with results to put in place interventions that support a woman's right to life and safe childbirth, and a child's right to life.

There is a need for the two systems to be mutually reinforcing. If well integrated, MPDSR can help to strengthen the CRVS system by providing a more holistic picture of mortality, particularly when more deaths are captured in the MPDSR system than officially registered with civil registration. Deaths found in the CRVS system but not in MPDSR allow for identifying gaps and for a more complete register of deaths during pregnancy, delivery, abortion or the post-partum periods, which can then be investigated by cause. This creates a more comprehensive assessment of the extent of maternal and perinatal deaths and a better understanding of the causes of death, allowing policymakers to respond, supporting pregnant women at increased risk and creating more effective interventions to prevent maternal and perinatal deaths. It also helps to improve the quality of care and measure quality of care improvements.

## Problem statement

**This section should provide a detailed description of the problem/issue/challenge and why solving the problem is important. Remember to use as much 'hard' evidence as possible – such as the number of maternal and/or perinatal deaths in the country, estimated completeness of birth and death registration, functionality of the CRVS and MPDSR systems, etc. Sample text is provided below, which can be updated with your data or replaced entirely.**

Maternal and perinatal mortality in [country] remains unacceptably high: in [year], an estimated [number of deaths] women died due to complications related to pregnancy and childbirth – equating to some [number] deaths each [day/week/month – **if the country has high maternal mortality, show the number of deaths per day or week, if mortality is low, you may want to show the number of deaths per month**]. Further, of the estimated [number] deaths among children aged less than [age – **for example 15 years, or five years**], [number] of these occurred among [age – **for example, newborns (early/late neonatal deaths) or infants less than one**].

**The next two paragraphs should briefly outline the CRVS and MPDSR systems, including any major issues and challenges as they relate to the identification and registration of maternal and perinatal deaths.**

## Options

Here you can briefly explain the current options (and impact), focussing on:

1. **Doing nothing**
2. **Cross-checking aggregate data**
3. **Validating aggregate data**
4. **Linking unit-record data.**

## Recommendation

**Here you can explain the recommended option. Refer to the project planning template for key information about what type of integration is being recommended, who will be involved, how the process will be managed, etc.**

## Conclusion

**Remember to keep the conclusion succinct and provide a high-level overview of the problem, options and recommendation(s).**

## Reference list

1. United Nations Economic and Social Commission for Asia and the Pacific. Asia-Pacific Guidelines to Data Integration for Official Statistics. Bangkok, Thailand: UNESCAP; 2021.
2. Emery J, Boyle D. Data linkage. *The Royal Australian College of General Practitioners*. 2017;46(8).
3. WHO. Building Back Better: Sustainable Mental Health Care after Emergencies. Geneva, Switzerland: World Health Organization; 2013.
4. WHO. Maternal death surveillance and response: technical guidance information for action to prevent maternal death. Geneva, Switzerland: World Health Organization; 2013.
5. WHO. Time to respond. A report on the global implementation of Maternal Death Surveillance and Response. Geneva, Switzerland: World Health Organization; 2016.
6. WHO. Making Every Baby Count. Audit and review of stillbirths and neonatal deaths. Geneva, Switzerland: World Health Organization; 2016.
7. Department of Economic and Social Affairs. Principles and Recommendations for a Vital Statistics System. Revision 3. New York: United Nations; 2014.
8. UNFPA. State of World Population 2020. New York, USA: United Nations Population Fund; 2020.
9. AbouZahr C. Making sense of maternal mortality estimates. Brisbane, Queensland: Health Information Systems Knowledge Hub, University of Queensland; 2010.
10. Thomas L-M, D'Ambruso L, Balabanova D. Use of verbal autopsy and social autopsy in humanitarian crises. *BMJ Global Health*. 2018;3(3):e000640.
11. Scott H, Danel I. Accountability for improving maternal and newborn health. *Best Practice & Research Clinical Obstetrics & Gynaecology*. 2016;36:45-56.
12. UNFPA ASRO. Saving mothers lives through advancing maternal death surveillance & response (MDSR) systems. Arab States Regional MDSR Workshop. Cairo, Egypt: United Nations Population Fund Arab States Regional Office; 2019.
13. UNFPA ASRO. Assessment of maternal death surveillance and response system. Case studies from selected Arab countries. Cairo, Egypt: United Nations Population Fund Arab States Regional Office; 2017.

14. Secretariat NM. Saving Mother's Lives. Confidential inquiry into maternal deaths in Kenya. First report. Nairobi, Kenya: Ministry of Health; 2017.
15. Centre of Excellence for Civil Registration and Vital Statistics (CRVS) Systems. Compendium of Good Practices in Linking Civil Registration and Vital Statistics (CRVS) and Identity Management Systems. Ottawa, Canada: International Development Research Centre; 2019.
16. Badiee S, Appel D. Harnessing CRVS Systems for the Gender-Related SDGs - Opportunities and Challenges. Ottawa, ON: Centre of Excellence for Civil Registration and Vital Statistics Systems, International Development Research Centre; 2019.
17. WHO. Beyond the numbers: reviewing maternal deaths and complications to make pregnancy safer. Geneva, Switzerland: World Health Organization; 2004.
18. Kerber KJ, Mathai M, Lewis G, Flenady V, Erwich JJHM, Segun T, et al. Counting every stillbirth and neonatal death through mortality audit to improve quality of care for every pregnant woman and her baby. *BMC Pregnancy and Childbirth*. 2015;15(2):S9.
19. Smith H, Ameh C, Roos N, Mathai M, Broek Nvd. Implementing maternal death surveillance and response: a review of lessons from country case studies. *BMC Pregnancy and Childbirth*. 2017;17(1):233.
20. SEARO. Strengthening country capacity on maternal and perinatal death surveillance and response. World Health Organization Regional Office for South-East Asia; 2016.
21. Bayley O, Chapota H, Kainja E, Phiri T, Gondwe C, King C, et al. Community-linked maternal death review (CLMDR) to measure and prevent maternal mortality: a pilot study in rural Malawi. *BMJ Open*. 2015;5.
22. Sunguya B, Thapa K, Kinney M, Lemwayi R, Mwaitenda US. Assessment of Maternal and Perinatal Death Surveillance and Response (MPDSR) Implementation in Kagera and Mara Region, Tanzania. USAID; 2018.
23. Biswas A. Shifting paradigm of maternal and perinatal death review system in Bangladesh: A real time approach to address sustainable developmental goal 3 by 2030. *F1000Res*. 2017;6:1120-.
24. Mukinda FK, Belle SV, George A, Schneider H. The crowded space of local accountability for maternal, newborn and child health: a case study of the South African health system. *Health Policy and Planning*. 2019;35(3):279-90.
25. de Sousal MH, Cecattil JG, Hardyl EE, Serruya SJ. Declared maternal death and the linkage between health information systems. *Revista de Saude Publica*. 2007;41(2).

26. Kongnyuy EJ, van den Broek N. The difficulties of conducting maternal death reviews in Malawi. *BMC Pregnancy and Childbirth*. 2008;8(42).
27. Graham W, Ahmed S, Stanton C, Abou-Zahr C, Campbell O. Measuring maternal mortality: An overview of opportunities and options for developing countries. *BMC Medicine*. 2008;6(12).
28. de Savigny D, Riley I, Chandramohan D, Odhiambo F, Nichols E, Notzon S, et al. Integrating community-based verbal autopsy into civil registration and vital statistics (CRVS): system-level considerations. *Global Health Action*. 2017;10(1272882).
29. Bandali S, Thomas C, Wamalwa P, Mahendra S, Kaimenyi P, Warfa O, et al. Strengthening the “P” in Maternal and Perinatal Death Surveillance and Response in Bungoma county, Kenya: implications for scale-up. *BMC Health Services Research*. 2019;19(1):611.
30. de Savigny D, Renggli S, Cobos Munoz D, Collinson M, Sankoh O. Maximising synergies between Health Observatories and CRVS: Guidance for INDEPTH HDSS Sites and CRVS Stakeholders. Melbourne, Australia: INDEPTH Network and Bloomberg Data for Health Initiative; 2018.
31. Shittu O, Kinney M. Assessment of Maternal and Perinatal Death Surveillance and Response Implementation in Nigeria. Ministry of Health; 2017.
32. Dusetzina S, Tyree S, Meyer A, Meyer A, Green L, Carpenter W. Linking data for health services research: A framework and instructional guide. Rockville, MD: Agency for Healthcare Research and Quality; 2014. Available from: <https://www.ncbi.nlm.nih.gov/books/NBK253312/>.
33. Harron K, Gilbert R, Cromwell D, van der Meulen J. Linking Data for Mothers and Babies in De-Identified Electronic Health Data. *PLoS One*. 2016;11(10):e0164667.
34. Joubert J, Bradshaw D, Kabudula C, Rao C, Kahn K, Mee P, et al. Record-linkage comparison of verbal autopsy and routine civil registration death certification in rural north-east South Africa: 2006–09. *International Journal of Epidemiology*. 2014;43(6):1945-58.
35. Marskell J, Sorchik R. Bali Process Civil Registration Assessment Toolkit. Thailand, Bangkok: The Bali Process; 2018.
36. UNICEF. Birth registration and armed conflict. Innocenti Research Centre, United Nations Children's Fund; 2007.
37. APAI-CRVS. Civil Registration and Conflict in Emergency Situations. Addis Ababa, Ethiopia: Africa Programme for Accelerated Improvement of Civil Registration and Vital Statistics; ND.

38. WHO, UNICEF, Save the Children, UNHCR, CDC, UNFPA. Experts Meeting on Maternal and Perinatal Death Surveillance and Response (MPDSR) in Humanitarian Settings. New York, USA: United Nations Children's Fund; 2019.
39. Casey SE, Chynoweth SK, Cornier N, Gallagher MC, Wheeler EE. Progress and gaps in reproductive health services in three humanitarian settings: mixed-methods case studies. *Conflict and Health*. 2015;9 (Suppl 1)(53).
40. Đoković Z, Dincu I, Slotin J. Compendium of good practices in linking civil registration and vital statistics (CRVS) and identity management systems. Synthesis of case studies. Ottawa, Canada: Centre of Excellence for Civil Registration and Vital Statistics Systems; 2019.
41. UNHCR. Guidance on the Protection of Personal Data of Persons of Concern to UNHCR. Geneva, Switzerland: United Nations High Commissioner for Refugees; 2018.
42. European Parliament. General Data Protection Regulation. European Union; 2016.
43. Brown AP, Ferrante AM, Randall SM, Boyd JH, Semmens JB. Ensuring Privacy When Integrating Patient-Based Datasets: New Methods and Developments in Record Linkage. *Frontiers in Public Health*. 2017;5(34).
44. University of Melbourne. Strengthening CRVS systems through effective legislation. Melbourne, Australia: Bloomberg Philanthropies Data for Health Initiative, Civil Registration and Vital Statistics Improvement, University of Melbourne; 2018.
45. Muriuki D. Contribution of NGOs in Complex Emergencies. 2005.
46. Maternal and Child Survival Program. Assessment of Maternal and Perinatal Death Surveillance and Response Implementation in Ebonyi and Kogi States, Nigeria. USAID; 2017.
47. Kurinczuk J, Draper E, Field D, Bevan C, Brocklehurst P, Gray R, et al. Experiences with maternal and perinatal death reviews in the UK—the MBRRACE-UK programme. *BJOG: An International Journal of Obstetrics & Gynaecology*. 2014;121(s4):41-6.
48. Livingston A. Civil Registration and Legal Identity in Humanitarian Settings: The London School of Economics and Political Science; 2019 [Available from: <https://blogs.lse.ac.uk/mec/2019/05/03/civil-registration-and-legal-identity-in-humanitarian-settings/>].
49. UNFPA. Maternal Death Surveillance and Response: Inventory of current practices in humanitarian settings supported by UNFPA. United Nation's Population Fund; 2020.

50. Hynes M, Sakani O, Spiegel P, Cornier N. A Study of Refugee Maternal Mortality in 10 Countries, 2008–2010. *International Perspectives on Sexual and Reproductive Health*. 2012;38(4):205-13.
51. de Savigny D, Cobos Munoz D. *Understanding CRVS systems: The importance of process mapping*. Melbourne, Australia: Bloomberg Philanthropies Data for Health Initiative, Civil Registration and Vital Statistics Improvement, the University of Melbourne; 2018.
52. The University of Melbourne. *CRVS best-practice and advocacy. Intervention: Improving CRVS system design*. Melbourne: The University of Melbourne, Bloomberg Philanthropies Data for Health Initiative; 2016.
53. Biswas A, Rahman F, Eriksson C, Dalal K. Community Notification of Maternal, Neonatal Deaths and Still Births in Maternal and Neonatal Death Review (MNDR) System: Experiences in Bangladesh. *Health*. 2014;6(16):2218-26.
54. OCHA. *Symposium on best practices in humanitarian information exchange*. Geneva, Switzerland: United Nations Office for the Coordination of Humanitarian Affairs; 2002.
55. Koblinsky M. Maternal Death Surveillance and Response: A Tall Order for Effectiveness in Resource-Poor Settings. *Global Health: Science and Practice*. 2017;5(3):333-7.
56. Muzzi M. *UNICEF good practices in integrating birth registration into health systems (2000–2009: case studies: Bangladesh, Brazil, The Gambia and Delhi, India*. New York, USA: United Nations Children’s Fund; 2009.
57. Smith H, Ameh C, Godia P, Maua J, Bartilol K, Amoth P, et al. *Implementing Maternal Death Surveillance and Response in Kenya: Incremental Progress and Lessons Learned*. *Global Health: Science and Practice*. 2017;5(3):345-54.
58. Walle B, Van Den Eede G, Muhren W. *Humanitarian Information Management and Systems Global Symposium+5; 22-26 October 2007; Geneva, Switzerland 2008*. p. 12-21.
59. Bo K, Firth S, Hudson S. *Advocating for change: How advocacy contributed to strengthened civil registration and vital statistics in Myanmar*. Melbourne, Australia: Bloomberg Philanthropies Data for Health Initiative, University of Melbourne; 2020.
60. APAI-CRVS. *Civil Registration and Vital Statistics Digitisation Guidebook. Version 0.10*. Africa Programme for Accelerated Improvement of Civil Registration and Vital Statistics; 2015.

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