





# **CRVS** analyses and evaluations

Where there is no physician: Improving the notification of community deaths

July 2018





# Resources available from the University of Melbourne, Bloomberg Philanthropies Data for Health Initiative

#### CRVS course prospectuses

These resources outline the context, training approach, course content and course objectives for the suite of CRVS trainings delivered through the Bloomberg Philanthropies Data for Health Initiative. Each course focuses on a specific CRVS intervention or concept, and is designed to support countries to strengthen their CRVS systems and data.

#### CRVS Fellowship reports and profiles

The CRVS Fellowship Program aims to build technical capacity in both individuals and institutions to enhance the quality, sustainability and health policy utility of CRVS systems in Fellows' home countries. *Fellowship reports* are written by Fellows as a component of the program, and document, in detail, the research outcomes of their Fellowship. *Fellowship profiles* provide a summary of Fellows' country context in relation to CRVS, an overview of the Fellowship experiences, the research topic and the projected impact of findings.

#### CRVS analyses and evaluations

These analytical and evaluative resources, generated through the Initiative, form a concise and accessible knowledge-base of outcomes and lessons learnt from CRVS initiatives and interventions. They report on works in progress, particularly for large or complex technical initiatives, and on specific components of projects that may be of more immediate relevance to stakeholders. These resources have a strong empirical focus, and are intended to provide evidence to assist planning and monitoring of in-country CRVS technical initiatives and other projects

### CRVS best-practice and advocacy

Generated through the Initiative, CRVS best-practice and advocacy resources are based on a combination of technical knowledge, country experiences and scientific literature. These resources are intended to stimulate debate and ideas for in-country CRVS policy, planning, and capacity building, and promote the adoption of best-practice to strengthen CRVS systems worldwide.

#### CRVS country reports

CRVS country reports describe the capacity-building experiences and successes of strengthening CRVS systems in partner countries. These resources describe the state of CRVS systems-improvement and lessons learnt, and provide a baseline for comparison over time and between countries.

#### CRVS technical guides

Specific, technical and instructive resources in the form of *quick reference guides, user guides* and *action guides*. These guides provide a succinct overview and/or instructions for the implementation or operation of a specific CRVS-related intervention or tool.

#### CRVS tools

Interactive and practical resources designed to influence and align CRVS processes with established international or best-practice standards. These resources, which are used extensively in the Initiative's training courses, aim to change practice and ensure countries benefit from such changes by developing critical CRVS capacity among technical officers and ministries.

Published by the University of Melbourne, Civil Registration and Vital Statistics Improvement, Bloomberg Philanthropies Data for Health Initiative.

Melbourne School of Population and Global Health Building 379 207 Bouverie Street Carlton, VIC 3053 Australia

CRVS-info@unimelb.edu.au www.mspqh.unimelb.edu.au/dataforhealth

# Made possible through funding from Bloomberg Philanthropies

www.bloomberg.org

#### Suggested citation

Cobos Muñoz D, de Savigny D. Where there is no physician: improving the notification of community deaths. CRVS technical outcome series. Melbourne, Australia: University of Melbourne, Civil Registration and Vital Statistics Improvement, Bloomberg Philanthropies Data for Health Initiative; 2018.

#### Acknowledgements

Carla AbouZahr, Tim Adair, Claire Brolan, Nicola Richards, Renee Sorchik and Alan Lopez, University of Melbourne; Martin Bratschi, Vital Strategies; Sam Notzon, Emily Cercone, Cathy Molchan Donald, Olga Joos, Brian Munkombwe and Erin Nichols, Centers for Disease Control and Prevention; Alvin Onaka, Government of Hawaii; Steve Schwartz, New York State Department; and Jeff Montgomery, New Zealand Department of Internal Affairs.

Abbreviations	ii
Key terms	ii
Executive summary	1
Strengthening mortality data through counting deaths	1
The importance of notifying community deaths	2
Examining community death notification practices: Country checklists	2
Examining community death notification practices: Process mapping	3
Community death notification processes in D4H countries	6
Death notification processes	7
Death notification forms	7
Agents involved in death notification	7
Active and passive notification processes	8
Link between notification and registration	8
Recommendations	8
Moving towards the universal digital notification-registration of community deaths	9
Summary	9
Annex 1: Draft generic death notification-registration form for community deaths	10
Related resources and products	12
University of Melbourne, D4H Initiative, CRVS Knowledge Gateway: Library	12
University of Melbourne, D4H Initiative, CRVS Knowledge Gateway: Learning Centre	12
University of Melbourne, D4H Initiative, CRVS Knowledge Gateway: Courses	12
Further reading	13

# **Abbreviations**

COD cause of death

CRVS civil registration and vital statistics

D4H Data for Health

ICD International Classification of Diseases

SOP standard operating procedure

VA verbal autopsy

WHO World Health Organization

# Key terms

Cause of death:	refers to 'all those diseases, morbid conditions or injuries which either resulted in or contributed to death and the circumstance of the accident or violence which produced any such injuries' (Twentieth World Health Assembly, 1967).
Community deaths:	refer to those deaths that take place outside of a formal health facility (such as at home, at the workplace, while in transit) and, as such, are not attended by a medical physician.
Death notification:	refers to the capture and onward transmission of minimum essential information on the fact of death by a designated agent or official of the CRVS [civil registration and vital statistics] system using a CRVS authorised death notification form (paper or electronic), with that transmission of information being sufficient to support eventual registration and certification of death.
Death declaration:	is 'the point in time at which a health professional, having determined that an individual is dead, formally states this finding' (World Health Organization, 2012).
Process mapping:	is becoming an essential early step in the comprehensive assessment of any CRVS system. A process map is a visual snapshot of the end-to-end activities, stakeholders and requirements of a CRVS system.
Standard operating procedures:	are detailed instructions compiled by an organisation to help workers carry out complex routine activities or tasks.
Verbal autopsy:	is a structured interview carried out with family members and/or caregivers of the deceased to elicit signs and symptoms and other important information that can be used to assign a probable underlying cause of death

# Where there is no physician: Improving the notification of community deaths

## **Executive summary**

Globally, an estimated two-thirds of all deaths occur at home (ie in the community setting), are not attended by a physician and remain unregistered. Therefore, as most deaths occur in the community, scaling up formal notification of community deaths in civil registration and vital statistics (CRVS) systems is a crucial task facing many countries. Occurrence of a death in the community, and the formal notification of that death event to a recognised, established government body or agency, is tremendously important. Notification is the gateway to all administrative, legal and statistical processes related to the vital event. However, countries often under-appreciate the policy value of compiling, transmitting, consolidating and using death notifications. At a foundational level, accurate and reliable counting of deaths and causal attribution of morbidity and mortality provide technical information that is essential for population health policy and planning, resource allocation, monitoring and evaluation, as well as redressing health inequities and responding to emerging health threats and epidemics.

Notification of deaths, particularly deaths in the community, requires special attention and will likely need specific interventions tailored to each country. This *CRVS technical outcome series* paper, therefore, not only highlights the importance of community death notification, but provides checklists for countries seeking to audit and improve internal notification of community deaths. Results from applying these checklists as part of a broader process mapping exercise with 16 countries will also be discussed, which in turn influenced the development of seven general guiding principles for the development of death notification forms. These resources are meant to aid countries and their CRVS partners as they move towards improving notification and registration of community deaths, particularly when considering universal digital notification-registration where there is no physician.

# Strengthening mortality data through counting deaths

The Bloomberg Philanthropies Data for Health (D4H) Initiative is tasked with supporting 18 countries and two cities to strengthen their civil registration and vital statistics (CRVS) systems. D4H assists countries to assess their CRVS systems, develop improvement plans, improve registration practices, specifically improve cause of death (COD) assignment using internationally recognised standards, and produce high-quality vital statistics.

Concerning mortality data, technical specialists from D4H have worked with 16 of the 18 countries to analyse their CRVS process – from the occurrence of a death, to its notification, registration, certification and eventual incorporation into the vital statistics system. Cross-country comparisons of these death registration processes have identified two separate but linked issues: those that arise from the notification of deaths occurring in health facilities such as hospitals, and those arising from the notification of community deaths.

Currently, deaths that occur in health facilities are often formally notified to the civil registration authorities, especially if the decedent was attended by a physician who completed a Medical Certificate of Cause of Death in accordance with World Health Organization (WHO) International Classification of Diseases (ICD) standards. However, some deaths in hospitals do escape the medical records unit and hence are not notified to authorities. Additionally, while hospitals know about cases such as 'dead on arrival', 'gone home to die', and so on, they often do not capture these events in their notification systems.

However, this problem is even greater for deaths that take place in the community setting. Globally, an estimated two-thirds of all deaths occur at home (ie in the community), are not attended by a physician and remain unregistered. Therefore, as most deaths occur in the community – and it is these deaths that are overwhelmingly unaccounted for by authorities – scaling up formal notification of community deaths in CRVS systems is a crucial task facing many countries.

de Savigny D, et al. Integrating community based verbal autopsy into civil registration and vital statistics (CRVS): system-level considerations. *Global Health Action* 2017; 10(1):1272882.

# The importance of notifying community deaths

A formal notification or declaration is an essential first step to enable deaths to be officially registered by the civil registrar and included in vital statistics. The WHO defines notification as:

The issuance by an appropriate authority of a form confirming the occurrence of a vital event. It may be used to obtain a burial permit but does not have the legal status of a death certificate.<sup>2</sup>

A declaration of death, on the other hand, is defined by the WHO as:

The point in time at which a health professional, having determined that an individual is dead, formally states this finding.<sup>3</sup>

For this paper, the working definition of the notification of death is as follows:

The capture and onward transmission of minimum essential information on the fact of death by a designated agent or official of the CRVS system using a CRVS authorised death notification form (paper or electronic), with that transmission of information being sufficient to support eventual registration and certification of death.

It should be noted, however, that the latest United Nations *Principles and recommendations for a vital statistics system* does not include the term 'notification' but instead refers to 'declaration' and 'informants' to refer to this step in the process.<sup>4</sup>

The occurrence of a death in the community, and the formal notification of that death to a recognised, established government body or agency such as a civil registry office or designated agent, the Ministry of Health or a community worker, is tremendously important. Notification is the gateway to all administrative, legal and statistical processes related to the vital event. Notification may be key for issuance of a burial or cremation permit. Notification of a death is crucial for eventual registration and certification, allowing surviving next of kin to access ownership and property, business or inheritance entitlements, or other health, housing and social welfare rights and entitlements.

However, countries often under-appreciate the policy value of compiling, transmitting, consolidating and using death notifications. At a foundational level, accurate and reliable counting of deaths and causal attribution of morbidity and mortality provide technical information that is essential for population health planning, resource allocation (both financial and human), monitoring and evaluation, and improvement in program performance, as well as redressing health inequities. In other words, unless countries have been notified about events occurring within their populations – populations that are not homogeneous but are frequently diverse and geographically disparate – they cannot develop responsive and equitable public health and related socioeconomic policies. Indeed:

Real-time and accurate statistics on mortality and COD are essential for the development of national health and population policies, and underpin the ability of countries to respond to emerging health threats and epidemics.<sup>5</sup>

# Examining community death notification practices: Country checklists

Through engaging in process mapping with countries as part of D4H (**Box 1**), two checklists for countries seeking to audit and improve internal notification of community deaths have been created and tested.

The first checklist relates to broader process and systems questions (**Checklist 1**). These are the main features of the notification process for deaths in the community.

The second checklist relates to the content of a country's formal notification form for community deaths (**Checklist 2**).

As outlined in Checklist 2, in assessing the existing notification forms for community deaths, countries need to consider whether their official notification form contains six key elements to elicit key notification information:

- unique identification record number
- details on the deceased (for statistical purposes)
- relevant details on the death event
- details of the person notifying the authorities of the death event (ie the declarant or informant)

<sup>2</sup> World Health Organization. CRVS eLearning materials. Module 6: death registration (draft). Geneva, Switzerland: WHO; 2017.

<sup>3</sup> World Health Organization. International guidelines for the determination of death – phase I (forum report). Ottawa, Canada: Canadian Blood Services; 2012.

<sup>4</sup> United Nations Department of Economic and Social Affairs (Statistical Division). *Principles and recommendations for a vital statistics system, revision 3.* New York, USA: United Nations; 2014.

<sup>5</sup> de Savigny D, et al. Integrating community based verbal autopsy into civil registration and vital statistics (CRVS): system-level considerations. Global Health Action 2017; 10(1):1272882.

### Box 1: Process mapping and modelling

A process map is a visual snapshot of the stakeholders, their end-to-end activities or processes, and the process requirements of the country's CRVS system. When undertaking a process mapping exercise for CRVS systems strengthening, countries aim to create maps for four CRVS systems processes:

- 1. Births in the community
- 2. Births in health facilities
- 3. Deaths in the community
- 4. Deaths in health facilities.

Process maps capture the complexity of CRVS systems in a single diagram that shows the stakeholders involved in a process and their interactions, responsibilities and tasks assigned.

In health systems, having such a comprehensive and shared view of system processes helps to understand stakeholders' relationships, identify bottlenecks, inefficiencies and design flaws that limit the performance of the system, and support the integration of new interventions in the system as well as dynamically model, monitor and manage change over time, once they are implemented. Process mapping is a tool for seeing the whole, and how various stakeholders fit and play their role ... Process mapping can be used for communicating, analysing, sense-making and managing.

Source: Cobos Muñoz D, de Savigny D. Process mapping and modelling: a tool for analysing and driving health systems change. In: de Savigny et al (eds). Applied systems thinking for health systems research: a methodological handbook. London, UK: Open University Press, McGraw Hill Education; 2017.

- documentation that declarant/informant may provide to confirm the death event or COD
- relevant details for the agent notified of the death

A disclaimer at the end of the checklist explains the intended use of the form and process for official registration.

The declarant/informant of a community death could be either an individual or an institution. The individual notifying the death event might be, for example, a relative of the deceased, neighbour or family friend. An institution notifying authorities of the death event may be a specific health facility, coroner, burial authority, local government authority, village authority, police, religious institution, or even a nongovernmental organisation or civil society actor.

# Examining community death notification practices: Process mapping

A process mapping exercise for notification of community deaths examines whether the notification process is described in an official document, or any other standard operating procedures (**Figure 1**). Some countries have a structured notification process for deaths that occur in health facilities, but not for deaths in the community. Some

countries have notification processes for community deaths, but these may not be well known to in-country CRVS stakeholders. Many countries have 'passive' notification systems that wait for the death to be declared to authorities by the family to trigger the registration process.<sup>6</sup>

Process mapping can also examine whether an official notification form specifically for community deaths or an official death notification form exists in the country. A form may exist but may not be called a death notification or record form. Indeed, a process mapping exercise may reveal that countries have multiple forms, which is confusing for CRVS stakeholders and inefficient from a systems improvement perspective.

The process mapping exercise will likely reveal that the notification process varies considerably, depending on country and context. Responsibility for notification of the death event may fall on the family of the deceased, health staff in public health facilities or in the private sector, community stakeholders, and/or local government authorities.

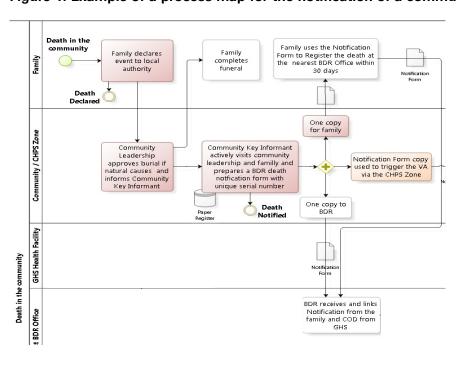
In many countries, however, the connection between notification of a death at community level and its subsequent registration/certification relies heavily on the family of the deceased. This is a lost opportunity and often formal notifications from passive systems can significantly outnumber officially registered events.

<sup>6 &#</sup>x27;Passive' notification refers to the conventional notification practice for community deaths of waiting for the family to declare the event to a local authority to start the CRVS process. This is why so few community deaths are ever registered. 'Active' notification, on the other hand, refers to the process whereby an agent of the CRVS or health system actively seeks out community deaths by managing and visiting community key informants or others such as those who issue burial permits, and then capturing the needed information for notification, or visiting the household to do so.

## Checklist 1: Main features of notification for deaths in the community

No.	Feature	Status
1	Is the notification process described in an official document?	Yes/No
2	Are there standard operating procedures (SOPs) regarding death notification?	Yes/No
3	Is the death notification process in the process map?	Yes/No
4	Number of agents/interactions involved for the declarant	[Insert number]
5	Health facility/system involved?	Yes/No
6	Who is the notification agent from the CRVS system for a death in the community?	[Insert name – Health staff? Local authority? Family?]
7	Who is the notification agent from the CRVS system for a death in a health facility?	[Insert name – Health staff? Other?]
8	Who makes the link between notification and registration?	[Insert specific individual, their role and/or agency - Health staff? Family? Automated/direct? None?]
9	Type of system for community deaths identification (passive vs active)	Passive/Active/Mixed
10	Is there an official death notification form?	Yes/No
11	Name of the official death notification form	[Insert country specific name]
12	Does the notification form have a unique ID or serial number?	Yes/No
13	Is there an official notification form specific for community (out of hospital) deaths?	Yes/No
14	Is the notification form detailed enough to register the death?	Yes/No
15	Can the notification form be used as a burial permit?	Yes/No
16	Is the burial permit issued with the notification form and not linked to registration?	Yes/No
17	Is the notification used to trigger verbal autopsy (VA)?	Yes/No

Figure 1: Example of a process map for the notification of a community death



# Checklist 2: Checking the content of a formal notification form for a community death

Element	Is this content included?						
On the form:	Administrative area to district, subdistrict, community level (usually to census administration level 5)						
	Unique serial number of the record (preferably automatically generated)						
	Date of notification						
For the deceased:	Full name						
	Personal identification number (if available)						
	Sex						
	Date of birth						
	Date of death						
	Age at death (if date of birth is not available)						
	Place of death						
	Usual place of residence						
For the death event:	Date and time of occurrence						
	Place of occurrence						
	Cause of death – if medically attended; manner or mode of death if not attended						
For the declarant/	Full name						
informant:	Personal identification number						
	Usual place of residence						
	Occupation						
	Relationship to the deceased						
	Telephone number and contact details						
	Date of reporting						
Documentation	Additional comments or remarks						
presented by declarant/ informant:	Declarant or informant's signature						
For the notification	Signature testifying to being notified						
agent:	Name						
	Title						
	Signature						
	Date						
Disclaimer:	Explaining that the completed notification form does not have legal status and is not a death certificate						
	Instructions for how the declarant/informant proceeds to register the death officially at a civil registry office (if such is the policy) – otherwise the notification agent takes care of transmission of the form for registration						

## Community death notification processes in D4H countries

A process mapping exercise for community deaths was conducted in collaboration with CRVS country stakeholders from 16 low- to middle-income countries involved in the D4H Initiative. The process mapping exercise aimed to develop a visual snapshot of the stakeholders, their end-to-end activities, and current CRVS process requirements for community deaths in each of these countries. **Table 1** presents the findings of the process mapping exercise.

Table 1: Main features of the notification process for community deaths in 16 low-to middle-income countries

Death notification feature	Bloomberg Data for Health country (de-identified)															
Death notification leature	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16
Is the notification process described in an official document?	Yes	No	Unsure	No	No	Yes	Yes	No	No	Partial	No	No	No	Yes	No	No
Are there standard operating procedures (SOPs) regarding death notification?	Yes	Yes	Unsure	No	No	No	No	No	No	No	No	No	No	Yes	No	No
Is the death notification process in the process map?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes
Number of agents/interactions involved for the declarant	1	1	3	1	2	1	1	3	1	4	2	2	2	1	2	3
Health facility/system involved?	Yes	Yes	Yes	No	No	No	No	Yes	Yes	Yes	Yes	No	Yes	No	No	Partial
Who is the notification agent from the CRVS system for a death in the community?	Health staff	Health staff	Health staff	Local authority	Family	Local authority	Local authority	Health staff	Health staff	Health staff	Health staff	Local authority	Health staff	Local authority	Local authority	Local authority
Who is the notification agent from the CRVS system for a death in a health facility?	Health staff	Health staff	Health staff	Health staff	Health staff	Health staff	Health staff	Health staff	Health staff	Health staff	Health staff	Health staff	Health staff	Health staff	Health staff	Health staff
Who makes the link between notification and registration?1	Health staff	Family	Family	Family	Family	Direct	Direct	Direct	Family	Family /Direct	Family	Family	None	Family	Family	Family
Type of system for community deaths identification (passive vs active)	Passive	Mixed	Passive	Mixed	Mixed	Passive	Passive	Passive	Passive	Passive	Passive	Mixed	Passive	Passive	Mixed	Passive
Is there an official death notification form?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes
Name of the official death notification form	No	Yes	Yes	Yes	No	Yes	Unsure	NA	Yes	NA	No	Yes	Yes	No	Unsure	Yes
Does the notification form have a unique ID or serial number?	Yes	No	No	Yes	Yes	Yes	Unsure	No	No	No	No	Yes	Yes	Yes	Yes	Yes
Is there an official notification form specific for community (out of hospital) deaths?	No	Yes	Yes	Yes	Yes	Yes	Yes	No	Unsure	NA	Yes	Unsure	Yes	Yes	Yes	No
Is the notification form detailed enough to register the death?	No	Unsure	Unsure	No	No	Yes	Yes	No	No	NA	No	Yes	No	No	No	Yes
Can the notification form be used as a burial permit?	NA	Unsure	Unsure	Yes	No	No	No	No	Yes	NA	No	Unsure	No	No	Yes	Yes
Is the burial permit issued with the notification form and not linked to registration?	Yes	Yes	NA	Yes	Yes	Unsure	Unsure	Yes	NA	NA	No	Yes	Yes	No	Yes	NA

NA = not applicable

1 'Direct link' means that the notification form is sent to the civil registry office using institutional channels, rather than indirectly through family members.

### **Death notification processes**

When examining whether the death notification process is described in an official document, or any other standard operating procedures (SOPs), it was found that, overall, notification processes are poorly designed and not very well known by CRVS stakeholders.

Some countries do not have any structured notification process for deaths that occur in the community. Only four of the 16 countries had an official document from the government where the notification process is described in some way. These are 'passive' notification systems waiting for the death to be declared to authorities by the family to trigger the registration process. Additionally, only three countries had SOPs outlining the process to notify a death in the community. Furthermore, the health system/facility is only involved in half the notification processes among the 16 countries. Therefore, it is not surprising that improving the notification of deaths is one of the major challenges facing countries seeking to strengthen their CRVS system and improve death registration completeness.

One of the few responsibilities that are defined in most countries (usually in some form of death registration act) is that a medically trained person must issue a Medical Certificate of Cause of Death, including for deaths that occur in the community. In five countries, the Medical Certificate of Cause of Death is used in those events as a death notification form that the family takes to the civil registry office as proof of the fact of death, and of the cause of death. Such processes bring with them their own set of complications that can hinder timely and complete registration.

Overall, results from this aspect of the process mapping highlight that clear processes for notifying community deaths are largely neglected in SOPs.

#### **Death notification forms**

The process mapping exercise examined whether an official notification form specifically for community deaths or an official death notification form exists in each of the 16 countries. Where a country did have a notification form, the seven elements in **Checklist 2** were further considered.

The minimum information requirements for notifying a death in the community are not clear in most of the 16 countries. Although most of these countries have some kind of form used for 'notification', only six have a specific form for deaths that occur outside of health facilities. Five countries use proxies such as an adapted version of the international Medical Certificate of Cause of Death, to which they add

some administrative data and information for statistical purposes. Three countries use multiple forms in the death notification processes, and two countries do not have an official notification form. Overall, nine of the 16 countries have a specific notification form for deaths occurring in the community.

Only half of the countries have a serial number on the notification form. In some cases, the number is generated at the local level with a combination of location codes, year and/or registration number. In others, the number is generated centrally and is either a computer-generated number or preprinted on the notification form.

### Agents involved in death notification

Among the 16 countries included as part of the process mapping, the notification process and agents involved in notifying community deaths vary considerably. For instance, responsibility for notifying the death event can fall on the family of the deceased, health staff either in public health facilities or in the private sector, community stakeholders, and/or local government authorities.

In most countries, it is not defined in the law or any other rules and regulations who should be involved in the notification of a death and precise responsibilities are poorly defined. In these countries, documents, protocols or SOPs that adequately define the responsibilities of these different actors are absent. This is either because these directives do not exist or because they are not readily available to CRVS system stakeholders.

Across the countries in which the CRVS system had an official notification step, a range of actors were authorised as notification agents. These ranged from health professionals, community health workers, traditional or trained birth attendants, village authorities, ward or subdistrict authorities, civil registration officials, community key informants, local government executive officers, government health workers, physicians in the private sector, police and local civil registry offices.

In most countries, multiple agents capture information about death events in different records. These actors are valuable assets to increase death registration since they are aware of deaths that are often never registered in the CRVS system. For example, several disease-focused health programs routinely collect information on deaths of target populations such as infants, children, pregnant women, and people with HIV/AIDS or tuberculosis. However, these programs usually operate in isolation and the information they gather is not shared or integrated into any official notification process.

### Active and passive notification processes

Death notification processes in most of the 16 countries were passive. Only five countries had some sort of active CRVS surveillance of death events occurring in the community. Note that where health professionals formally notify the civil registrar of the occurrence of a death using a standard template or form, this is considered active notification for those deaths. Prompted by the need for stronger notification processes for verbal autopsy (VA), three countries are in the planning phase of introducing active notification. Formalising the notification step represents a move towards active case finding and reporting of deaths through health institutions and community partners.

In passive systems, there are presently unmobilised, untrained, and unincentivised actors who could become agents in a more active notification system. Depending on context, these might include village chiefs, local government executive officers, government health workers, physicians in the private sector, police and local civil registry officers. There is also potential for other agents to become part of an active notification/registration system. These include community key informants, community health workers, and traditional or trained birth attendants.

## Link between notification and registration

The connection between the notification of a community death and its subsequent registration/certification currently relies heavily on the family of the deceased. The official registration process is usually triggered only if and when the family goes to the civil registry office with a notification form and/or witnesses. Only five of the 16 countries had a direct link using institutional channels between the agent that notifies the death and the civil registry office that validates the information and officially registers the event.

There is increasing interest in health facilities to capture vital statistical information on births and deaths, especially for children. However, this can only work well if a standard notification form is available that captures more than the conventional health record and is thus sufficient for the legal record (including identification of both the decedent and the declarant). Currently, most notification forms used in countries do contain the minimum information needed for the death to be registered. However, the registration law/ regulations often stipulate that the family must validate the registration through personal attendance at the civil registry office, even if the information has already been notified by the health sector.

One of the major incentives for the family to register the death of a relative is to obtain a burial or cremation permit. However, only in four countries is the death registration process triggered before or at the same time that the burial permit is issued. In the remaining countries, the family receives the notification form/burial permit first. Once they have received this, they have little incentive to continue the official registration process.

## Recommendations

Weaknesses in the critical initial step of the notification of community deaths are contributing enormously to low completeness rates in death registration and poor-quality mortality statistics. Such weaknesses also compromise efforts to provide comprehensive COD data from VA. Notification of deaths, particularly deaths in the community, needs special attention and will likely need specific interventions tailored to each country.

The following are some general guiding principles for countries and their partners to consider while moving towards improving notification and registration of community deaths:

- Conduct process mapping and, where necessary, a legal and regulatory review of notification processes using the checklists proposed here, to identify gaps and areas for improvement.
- Promote the use of alternative existing sources of information about deaths to co-opt into notification processes (eg community key informants, burial permit registers).
- **Promote** moving from passive to active notification processes and design appropriate forms, requirements, responsibilities and SOPs.
- **Ensure** that the new notification process translates to fully registered and certified deaths in the civil registration system.
- **Ensure** that the new notification process interoperates with community VA in a mutually reinforcing way, where appropriate.
- **Ensure** that a unique identifier is recorded on the notification form and that it will follow the vital event throughout the entire administrative (registration) and statistical process.
- **Collect** information only once and ensure that it can be shared with all legitimate agencies/sectors (ie move information, not people).

# Moving towards the universal digital notification-registration of community deaths

The introduction of VA for community deaths has highlighted the inconvenience and inefficiency of collecting the same information multiple times. Information is first collected when a death is notified and the VA is triggered. Subsequently, families are asked to spend significant time responding to a questionnaire that includes repeating information collected in the notification. Families are often also expected to travel to a civil registry office and validate the information already provided to officially register the death. In such circumstances, introducing VA could decrease registration coverage, the reverse of the effect desired.

This draws attention to the need to consider radically re-engineering system processes that would collapse the current separate steps of notification and registration into a single step. The increasing availability of practical mobile communication technologies at community level, plus the increasing moves to decentralise registration processes to designated agents closer to community level (or co-opt health staff for such purposes), makes such approaches feasible. It is possible to have a digital version of a death notification/registration form on a mobile device, collect the information at household level, and transmit it to central CRVS and health information management systems servers, along with digital signatures. Annex 1 provides an example of a form that captures all the information specified by the United Nations Statistical Division.7 The use of such a comprehensive notification form, one that serves the requirements of registration at the point of collection, could substantially improve the completeness of death registration in countries where the majority of deaths occur outside health facilities. This form works on paper, but could easily be digitised to harness the advantages of the digital approach. Digital data collection could also be used for deaths in health facilities, as even these are not always considered officially registered until the family has validated the information.

Countries introducing mobile digital VA in CRVS for community deaths are in an excellent position to test a single digital notification/registration step to enhance triggering of the eventual VA after a suitable bereavement period.

The challenge of notification/registration is pervasive across countries, and an important enough barrier to consider convening a multicountry and multipartner workshop to share experiences and discuss innovative approaches.

## **Summary**

Process mapping makes clear whether or not a country has an active or passive system for identifying and notifying community deaths, and whether there is an official death notification form specific for community deaths. The process mapping exercise carried out with 16 countries as part of the D4H Initiative revealed that the notification step is often poorly specified, highly variable in design, and sometimes missing completely from SOPs, forms and requirements.

This weakness is particularly apparent in settings where the majority of deaths occur in the community and where there is no physician. As a result, these deaths are not officially registered. Moreover, the absence of the notification step renders it difficult to introduce VA to determine the probable COD, as VA is dependent upon effective and timely notification of deaths to the registration and health authorities.

This CRVS technical outcome series paper summarises the findings from a review of 16 countries, and is intended to assist discussion of this topic by reviewing current practices and their implications. It provides a checklist that countries can use to assess their death notification processes, as well as guidelines on what to include on the death notification form, and what data would be necessary to collect to combine the notification and registration of a vital event. Overall, it is imperative to improve the processes connecting and combining notification with registration to strengthen CRVS performance and generate more reliable and complete mortality data.

<sup>7</sup> United Nations Department of Economic and Social Affairs (Statistical Division). *Principles and recommendations for a vital statistics system, revision 3*. New York, USA: United Nations; 2014.

# Annex 1: Draft generic death notification-registration form for community deaths

## A. DETAILS ABOUT THE DECEASED AND EVENT

Unique ID number for form	Enter NID or temporary ID centrally distributed
Full name of deceased	First name:
	Second name:
	Family name:
Sex of deceased	Male
	Ividie 🗀
	Female
	Unknown
Date of birth of deceased if known	Calendar (optional)
Date of death of deceased	Calendar
Age of deceased	Automatically calculated from DoB/DoD or entered or Unknown/categories
Name of parent(s) (if infant or child	Mother
death)	First name:
	Second name:
	Family name:
	Father
	First name:
	Second name:
	Family name:
Place of occurrence	Home
	Hospital
	Other health facility
	En route to health facility or hospital
	Other
	Don't know
Nature of death	Natural
	Unnatural (accident, etc) (assumes authorities notified)
	Unknown
Geographic location of death	District/Subdistrict/Community from drop down
Usual address or residence of deceased if known	District/Subdistrict/Community from drop down

# **B. DETAILS ABOUT THE INFORMANT**

8.	Full name of informant	First name:		
		Second name:		
		Family name:		
9.	Status of informant	Parent		
		Next of kin		
		Official		
		Other (specify)		
10.	Address of informant	Enter		
11.	Telephone number	Enter		
12.	Date of reporting	Calendar		
Declar	ration of Notification Agent (eg Communit	y Health Worker)		
l, as n	otification agent, hereby declare that I hav	ve been notified of the	ne death of:	
Decea	sed Name (carried forward from Decease	d Name) [		1
Digital	signature & ID of Notification Agent			
Digital	signature of Informant			

Note: This is not a burial permit or a death certificate.

# Related resources and products

## University of Melbourne, D4H Initiative, CRVS Knowledge Gateway: Library

#### crvsgateway.info/library

Action guide on process mapping for CRVS system-strengthening. CRVS action guides.

Improving registration: best practice guidelines. CRVS summaries.

Intervention: Improving CRVS system design. CRVS summaries.

Intervention: Improving registration practices. CRVS summaries.

Understanding CRVS systems: the importance of process mapping. CRVS development series.

# University of Melbourne, D4H Initiative, CRVS Knowledge Gateway: Learning Centre

#### crvsgateway.info/learningcentre

Topic 1: Introduction to CRVS.

Topic 2: CRVS governance and architecture – CRVS process mapping.

Topic 3: CRVS processes – The Ten CRVS Milestones framework.

Topic 4: Cause of death in CRVS – The value of cause of death data; Cause of death: where there is no physician; Automated verbal autopsy.

Topic 6: CRVS tools – CRVS system assessment tools; Process mapping.

## University of Melbourne, D4H Initiative, CRVS Knowledge Gateway: Courses

## crvsgateway.info/courses

Enterprise architecture/business process mapping for countries.

# **Further reading**

de Savigny D, et al. Integrating community-based verbal autopsy into civil registration and vital statistics (CRVS): system-level considerations. *Global Health Action*. 2017; 10(1):1272882.

United Nations Department of Economic and Social Affairs (Statistical Division). *Principles and recommendations for a vital statistics system, revision 3.* New York, USA: United Nations; 2014.







The program partners on this initiative include: The University of Melbourne, Australia; CDC Foundation, USA; Vital Strategies, USA; Johns Hopkins Bloomberg School of Public Health, USA; World Health Organization, Switzerland.

Civil Registration and Vital Statistics partners:







The University of Melbourne recognises the Swiss Tropical and Public Health Institute for their partnership and contribution



## For more information contact:

CRVS-info@unimelb.edu.au crvsgateway.info

CRICOS Provider Code: 00116K

Version: 0718-01

© Copyright University of Melbourne March 2018.

The University of Melbourne owns the copyright in this publication, and no part of it may be reproduced without their permission.

#### Disclaimer

The University of Melbourne has used its best endeavours to ensure that the material contained in this publication was correct at the time of printing. The University gives no warranty and accepts no responsibility for the accuracy or completeness of information and the University reserves the right to make changes without notice at any time in its absolute discretion.

#### Intellectual property

For further information refer to: unimelb.edu.au/governance/statutes