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IMPROVING CAUSE OF DEATH INFORMATION

Where there is no physician:
Notification of community
deaths in CRVS systems

CRVS Technical Outcome Series

October 2017





Contents

Abbreviations	iv
Executive Summary	1
1. Introduction	2
1.1 Process mapping and modelling	3
1.2 Importance of notification of a community death	3
2. Examining community death notification practices – checklists for countries	4
3. Process mapping notification of community deaths	6
4. Recommendations	7
4.1 Moving towards digital universal notification-registration of deaths where there is no physician	7



Abbreviations

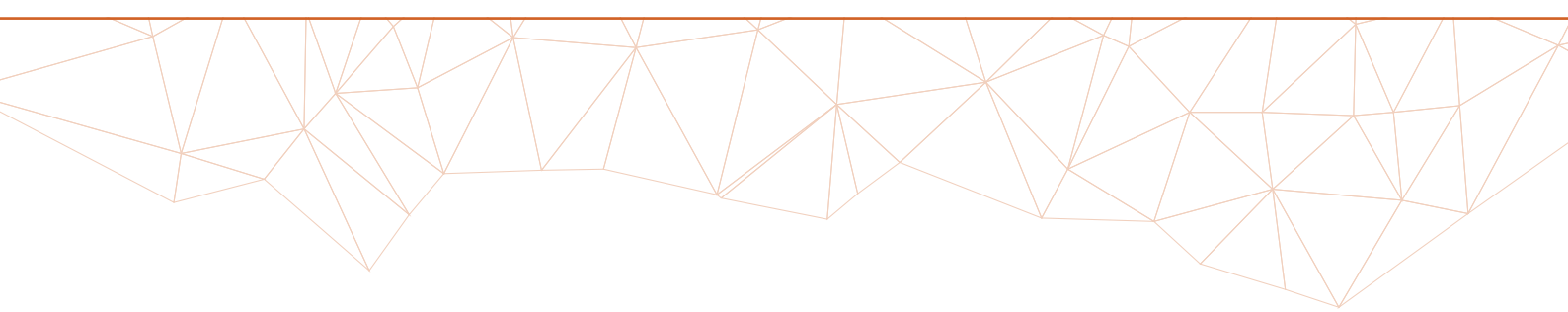
BD4H	Bloomberg Philanthropies Data for Health Initiative
COD	cause of death
CRVS	civil registration and vital statistics
UN	United Nations
VA	verbal autopsy
WHO	World Health Organization



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 event in the community, and the formal notification of that death event 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. However, countries often underappreciate the policy value of the compilation, transmission, consolidation and use of 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*, therefore, not only highlights the importance of community death notification, but will provide checklists for countries seeking to audit and improve internal notification of community deaths. It will also provide seven general guiding principles for countries and their CRVS partners to consider while moving towards improving notification and registration of community deaths, including digital universal notification-registration where there is no physician.



Where there is no physician: Notification of community deaths in CRVS systems

1 Introduction

The Bloomberg Philanthropies Data for Health Initiative (BD4H) is tasked with supporting 18 countries and two cities to strengthen their civil registration and vital statistics (CRVS) systems (Figure 1). BD4H 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 BD4H have worked with 16 of the 18 countries to analyse their CRVS process – from the occurrence of death, to its notification, registration, certification and eventual incorporation into the vital statistics system. These 16 low and middle-income countries are indicated in Figure 1.

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 standards. It is important to differentiate the separate issues that arise from notification of community events from notification of events occurring in health facilities such as hospitals. Hospitals know about cases such as 'dead on arrival', 'gone home to die', and so on, but they often do not capture these events in their notification systems. Certainly, some deaths in hospitals do escape the medical records unit and hence are not notified to authorities.

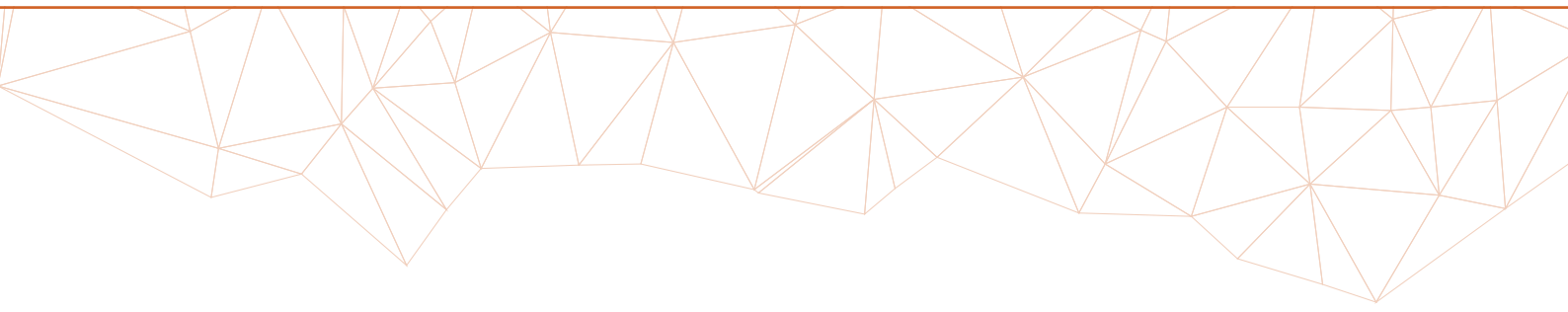



Figure 1: BD4H countries and cities¹

Countries	Cities
Bangladesh	Mumbai
Brazil	Shanghai
Colombia	
Ecuador	
Ghana	
Indonesia	
Kenya	
Malawi	
Myanmar	
Peru	
Philippines	
Papua New Guinea	
Rwanda	
Solomon Islands	
Sri Lanka	
Tanzania	
Turkey	
Zambia	

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 setting), are not attended by a physician, and remain unregistered.² 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.

1 Shaded countries are included in the review of notification processes.

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



1.1 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.'*³

1.2 Importance of notification of a community death

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. 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.'*⁴

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

*'The point in time at which a health professional, having determined that an individual is dead, formally states this finding.'*⁵


For the purpose of this *CRVS Technical Outcome Series*, however, 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.'

3 Cobos Muñoz D & D de Savigny (2017). Process mapping and modelling: A tool for analysing and driving health systems change. In: de Savigny D, Blanchet K & Adam T (eds). *Applied systems thinking for health systems research: a methodological handbook*. Open University Press, McGraw Hill Education: London, UK.

4 World Health Organization (2017). *CRVS eLearning materials. Module 6: death registration* (draft). WHO, Geneva.

5 World Health Organization (2012). *International guidelines for the determination of death – phase I* (forum report). Canadian Blood Services, Ottawa.



We note, however, that the latest United Nations (UN) *Principles and Recommendations for a Vital Statistics System* does not include the term 'notification' but instead refers to 'declarants' and 'informers' interchangeably.⁶

Occurrence of a death event in the community, and the formal notification of that death event 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 the death event is crucial for eventual registration and certification of the death, allowing surviving next of kin to unlock ownership and property, business, or inheritance entitlements, or other health, housing, and social welfare rights and entitlements. This is particularly the case for persons caught up in emergency and disaster-related settings.

However, countries often underappreciate the policy value of the compilation, transmission, consolidation and use of 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, 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 homogenous 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.'²

2 Examining community death notification practices – checklists for countries

Through engaging in process mapping with countries as part of BD4H, we have created and tested two checklists for countries seeking to audit and improve internal notification of community deaths. The first checks the features of the notification processes for deaths in the community (**Checklist 1**). The second checks the content of a country's formal notification form for deaths that occur in the community (**Checklist 2**).

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

⁶ UN Department of Economic and Social Affairs (Statistical Division) (2014). *Principles and recommendations for a vital statistics system, revision 3*. United Nations, New York. Available online: unstats.un.org/unsd/demographic/standmeth/principles/M19Rev3en.pdf

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

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

As outlined in **Checklist 2**, in assessing the existing notification forms for community deaths, countries need to consider whether their official notification form contains seven elements to elicit key notification information. The form should have a unique identification record number and ask for details on the deceased for statistical purposes, relevant details on the death event and the person notifying the authorities of the death event (ie the declarant or informant) and any documentation they may provide to confirm the death event or COD, as well as relevant details regarding the agent notified of the death event.

The declarant/informant of a community death could be either an individual or institution. The individual notifying of the death event might be, for instance, 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.

Checklist 2: Checking 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/ informant:	Full name Personal identification number Usual place of residence Occupation Relationship to the deceased Telephone number and contact details Date of reporting
Documentation presented by declarant/ informant:	Additional comments or remarks Declarant or informant's signature
For the notification agent:	Signature testifying to being notified Name Title Signature Date
Disclaimer:	Explaining that: <ul style="list-style-type: none"> ■ The completed notification form does not have legal status and is not a death certificate ■ Instruct 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



3 Process mapping notification of community deaths

A process mapping exercise for notification of community deaths will examine whether the notification process is described in an official document, or any other standard operating procedures. Some countries have a structured notification process for deaths that occur in health facilities, but not 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 by the family to authorities in order to trigger the notification to the civil registration and registration process.⁷

A process mapping exercise will then examine whether an official notification form specifically for community (out of hospital) deaths or an official death notification form exists in the country of interest. A form may exist but may not be specifically called a Death Notification Form (or Death Record Form). Indeed, the process mapping may reveal that countries have multiple forms, which is confusing for CRVS stakeholders and inefficient from a systems improvement perspective. Notification forms may not have serial numbers or may have serial numbers that are locally generated as opposed to a standardised, centrally generated serial number. There is increasing interest in using health facilities to capture vital statistical information on birth 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).

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 most countries, it is likely multiple agents will capture information about the death in different records. For example, several disease-focused health programs collect information on deaths in target populations such as infants, children, pregnant women and people with HIV/AIDS or tuberculosis. These programs usually operate in isolation and the information they gather is not integrated into any official notification process.

In passive systems, there are presently un-mobilised, untrained, and un-incentivised 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.

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. The official registration process is usually triggered only when the family goes to the civil registry office with a notification form and/or witnesses. This is a lost opportunity and often formal notifications from passive systems can significantly outnumber officially registered events.

7 By 'passive' notification we refer 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. By 'active' notification we refer to the process whereby an agent of the CRVS system 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.



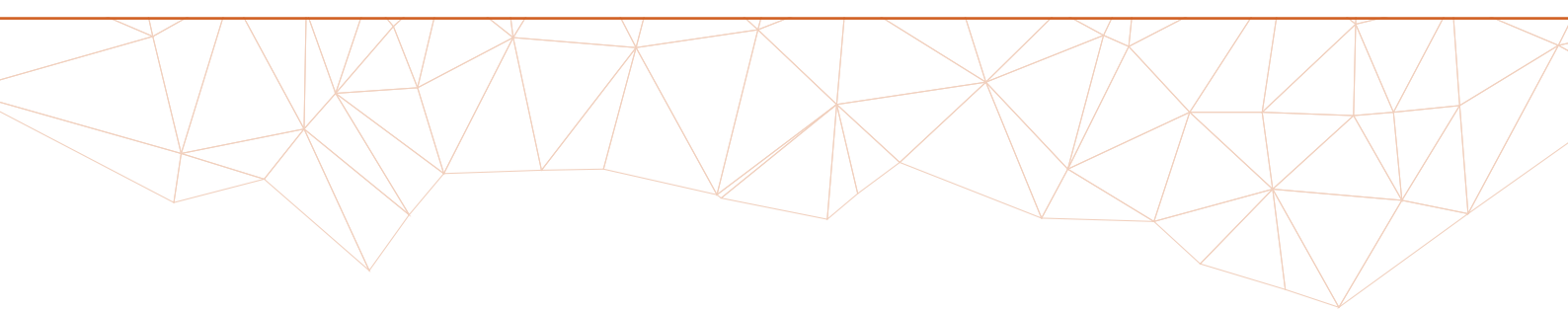
4 Recommendations

The weaknesses in the critical initial process of death notification for deaths occurring outside health facilities contribute enormously to low completeness rates in death registration and mortality statistics. Such weaknesses also compromise efforts to provide comprehensive COD data from verbal autopsy (VA).⁸ 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 toward 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
- 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 standard operating procedures
- Ensure that the new notification process translate 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 in the notification form and it will follow the vital event throughout the entire administrative (registration) and statistical (VA) process
- Collect information only once and ensure that it can be shared with all legitimate agencies/sectors (ie move information, not people).

8 Most countries will rely on the notification step to trigger the VA.



4.1 Moving towards digital universal notification-registration of deaths where there is no physician

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 in order 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 CRVS 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 management information systems servers (eg DHIS2), along with digital signatures. **Annex 1** provides an example of a form that captures all the information specified by the UN Statistical Division.⁶ 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 multi-country and multi-partner workshop to share experiences and discuss innovative approaches.



Related resources and products from the Bloomberg Philanthropies Data for Health Initiative

University of Melbourne (2017). MODULE 4.4 Cause of death – where there is no physician. Alan Lopez (Topic: Cause of death). Civil Registration and Vital Statistics Improvement Group, Bloomberg Philanthropies, Data for Health Initiative: Melbourne, Australia.

University of Melbourne (2017). Understanding country CRVS systems: The importance of mapping processes. CRVS Roadmaps for Action. Civil Registration and Vital Statistics Improvement Group, Bloomberg Philanthropies, Data for Health Initiative: Melbourne, Australia.

University of Melbourne (2017). Integrating community-based verbal autopsy into CRVS: System-level considerations. CRVS Technical Outcome Series. Civil Registration and Vital Statistics Improvement Group, Bloomberg Philanthropies, Data for Health Initiative: Melbourne, Australia.

University of Melbourne (2017). Introducing verbal autopsies into CRVS: Guiding principles. CRVS Technical Outcome Series. Civil Registration and Vital Statistics Improvement Group, Bloomberg Philanthropies, Data for Health Initiative: Melbourne, Australia.

University of Melbourne (2016). Improving registration practices. Overview flyer. Civil Registration and Vital Statistics Improvement Group, Bloomberg Philanthropies, Data for Health Initiative: Melbourne, Australia.



Annex 1: Draft generic death notification/registration form for digital universal notification/registration of deaths where there is no physician

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 <input type="checkbox"/> Female <input type="checkbox"/> Unknown <input type="checkbox"/>
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 death)	Mother First name: Second name: Family name:
	Father First name: Second name: Family name:
Place of occurrence	Home <input type="checkbox"/> Hospital <input type="checkbox"/> Other health facility <input type="checkbox"/> On route to health facility or hospital <input type="checkbox"/> Other <input type="checkbox"/> Don't know <input type="checkbox"/>
Nature of death	Natural <input type="checkbox"/> Unnatural (accident, etc) <input type="checkbox"/> (assumes authorities notified) Unknown <input type="checkbox"/>
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 <input type="checkbox"/> Next of kin <input type="checkbox"/> Official <input type="checkbox"/> Other (specify) <input type="checkbox"/>
10.	Address of informant	Enter
11.	Telephone number	Enter
12.	Date of reporting	Calendar

Declaration of Notification Agent (eg Community Health Worker)

I, as notification agent, hereby declare that I have been notified of the death of:

Deceased Name (carried forward from Deceased Name) []

Digital signature & ID of Notification Agent

Digital signature of Informant

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

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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:



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