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IMPROVING CAUSE OF DEATH INFORMATION

Addressing the
'scandal of invisibility' –
improving community
death notification

CRVS Roadmaps for Action

October 2017



Introduction

‘The persistent failure to establish, support, and sustain civil registration systems over the past 30 years, and to ensure that causes of death are accurately known in the world’s poorest countries is a scandal of invisibility, for which affordable remedies exist and need to be implemented. The scope of this scandal is enormous. Few countries in greatest need of vital events and information about cause of death have the capacity to obtain it.’¹

Civil registration is a process whereby major vital events occurring in a population are officially recorded. It is defined by the United Nations as *‘the continuous, permanent, compulsory and universal recording of the occurrence and characteristics of vital events in a population’*, in accordance with the legal requirements of the country.²

Countries can use information from strengthened civil registration and vital statistics (CRVS) systems to improve population health. Information on when, where and among whom deaths occur, and *cause of death*, allows countries to identify population health (including health equity) issues that they then can prioritise and respond to through evidence-based health (and intersectoral) policy and planning. Understanding the major causes of death is especially important in countries experiencing economic disadvantage, and where strategic investment of limited resources for health really counts.

Common roadblocks

Deaths usually occur in one of two places – in health facilities (that is, hospitals or clinics), or in the community (often the home). 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 WHO/International Classification of Diseases standards.³ It is important to separate the issues that arise from notification of community events from those that arise from notification of events occurring in health facilities such as hospitals. Hospitals know about cases like ‘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. 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 (that is, in the community setting), are not attended by a physician, and remain unregistered.⁴ 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 will be a crucial task for many countries in the future.

Bloomberg Philanthropies Data for Health Initiative’s working definition of the notification of death is:

‘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.’

¹ Setel PW, Macfarlane SB, Szreter S et al, on behalf of the Monitoring of Vital Events (MoVE) Writing Group (2007). A scandal of invisibility: making everyone count by counting everyone. *The Lancet* 370:1569–1577.

² 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

³ For more information on the WHO/International Classification of Diseases (ICD) standards, see: <http://www.who.int/classifications/icd/en/>

⁴ 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.

Moving forward

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. To improve information on deaths that take place in the community, countries will need to undertake a process mapping exercise for community deaths. 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. Process maps capture the complexity of CRVS systems in a single diagram that shows that stakeholders involved in a process and their interactions, responsibilities and tasks assigned.⁵ The process mapping exercise for community deaths should ideally be led or overseen by the national CRVS steering committee.

Through engaging in process mapping exercises with countries as part of the Bloomberg Philanthropies Data for Health Initiative, two checklists have been both created and tested for countries seeking to audit and improve internal notification of community deaths.

The first checklist relates to broader process and systems questions, and checks the features of the notification process for deaths in the community (**Checklist 1**). These are the main features of the notification process for deaths in the community, and 17 questions are asked.

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?]

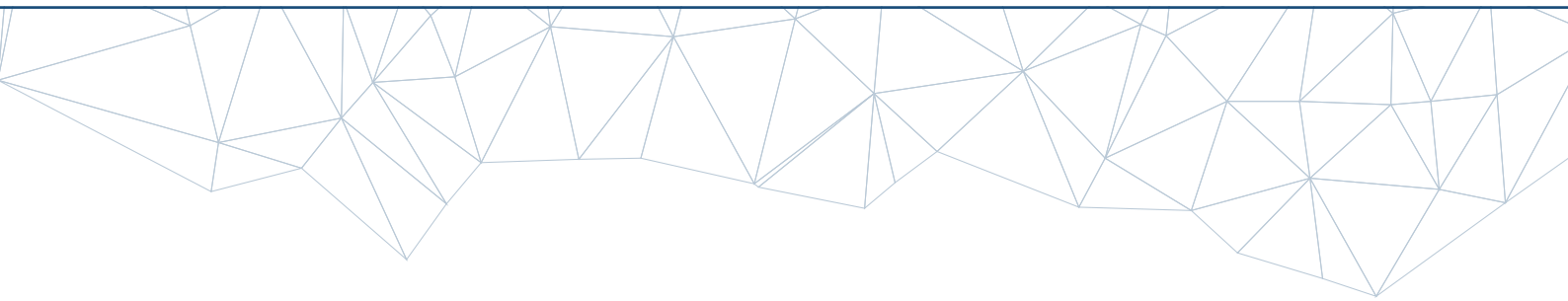
⁵ Cobos Muñoz D & D de Savigny (2017). Process mapping and modelling: A tool for analysing and driving health systems change. In: de Savigny D, Blanchet K & Adam T (eds). *Applied systems thinking for health systems research: a methodological handbook*. Open University Press, McGraw Hill Education: London, UK.



Checklist 2, on the other hand, checks the content of a country’s formal notification form (if such a form exists) for deaths that occur in the community. As outlined in **Checklist 2**, countries will need to consider whether their official notification form contains seven elements to elicit key notification information for community deaths.

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
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Summary

The weaknesses in the initial process of death notification for deaths occurring outside health facilities contribute enormously to low completeness rates in death registration and mortality statistics.⁶ Notification of deaths, particularly deaths in the community, needs special attention and will likely need specific interventions tailored to each country. Capturing community deaths will be key in addressing the ‘scandal of invisibility’, wherein people in many parts of the world – especially the poor, marginalised and unwell – are born and die without leaving a trace in any legal record or official statistic, rendering them ‘unseen, uncountable, and hence uncounted’.

⁶ Such weaknesses also compromise efforts to provide comprehensive cause-of-death data from verbal autopsy (VA) – most countries will rely on the notification step to trigger the VA.

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**DATA FOR
HEALTH INITIATIVE**



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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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