Sharing of death information across the Pacific

Audience: Pacific Civil Registrars Network
Presenter: Jeff Montgomery (New Zealand)

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Barriers and opportunities for sharing of cause of death information for citizens who die in another country. Followed by discussion and agreement on what PCRN and member countries should do next.

1. Background

Many Pacific Island countries and territories are unable to get accurate counts of birth, death and causes of death information. This lack of information affects local health and community planning, funding and priority planning and ability to access aid investment.

Many Pacific people are born in one country (often their home island) but die in another place (such as New Zealand or Australia). Traditionally original birth and death certificates are issued in the country of occurrence. As a result, such 'events' occurring overseas are often not registered in their home island, country or territory. This means that birth records are often left 'open' and therefore at risk of identity theft and local mortality statistics being incomplete.

This is in part due to the fact that many Pacific Island citizens are required to travel overseas for treatment when their local hospital does not provide the facilities or treatment necessary for their condition, have left their home island for economic reasons, or to be closer to family members. For many, this arrangement could be long term or even permanent, while for others this may be only a temporary arrangement.

Lack of investment across the Pacific region maintaining and developing CRVS systems, related IT hardware and technical support has resulted in inadequate and incompatible CRVS datasets.

There is an opportunity for New Zealand to share 'death' related information, with Pacific Island nations, of their citizens that have died in New Zealand. This will help improve the percentage of birth records that are 'closed' once the individual has died, and possibly provide more complete analysis on cause of death.

Pacific Island born people, living in New Zealand and Australia

Significant proportions of people born in the Pacific Islands no longer reside in their location of birth.

	Population estimate (2013)	**Born** in the Pacific, Currently living in NZ (2013 Census)	**Born** in the Pacific, **died** 2014 in NZ (NZ Life data)	**Born** in the Pacific, Currently living in AU (2011 Census)
Samoa	187,400	50,661	430	19,093
Cook Islands	15,200	12,954	205	6,092
Niue	1,611	4,197	57	703
Tokelau	1,200	1,338	23	525
Fiji	859,200	52,755	219	56,979
Tonga	103,300	22,416	242	9,209
Kiribati	108,800	1,473	3	500
Tuvalu	10,900	1,419	12	122
PNG	7,398,500	1,344	2	26,788
Vanuatu	253,763	-[1]	1	1,107

Over 50,000 Samoan born people, equivalent of approximately 37% of the country's population, live in New Zealand, with an additional 19,000 living in Australia.

The Cook Islands has approximately as many people who were born on the islands that live in New Zealand and Australia, as reside there.

In Niue and Tokelau, far more people born on the Islands reside in New Zealand and Australia than the total current populations living on their birth Island.

(Appendix 1 provides more detail, and the number of registered 'name change' and 'deaths' of people born in Samoa, Cook Islands, Niue or Tokelau people living in New Zealand and Australia.)

2. Opportunities to enable information sharing

This paper will not address the accuracy or completeness of registry information. This is being addressed by the wider UN and Brisbane Accord Group (BAG) work, but rather the barriers for getting the information sharing issues on the table and operating, so that once the accuracy of reporting is improved the mechanisms are already in place.

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[1] Data not captured in NZ Census 2013

For the purpose of this paper Samoa, Cook Islands, Niue and Tokelau have been used to provide BDM examples, however the opportunities, barriers and outcomes of sharing death information should be transferable across the Pacific region.

Why share BDM information – Opportunities

Having such large proportions of the birth population of the country unaccounted for, in respect of recording vital BDM information, results in accurate counts of births, deaths and causes of death not being available to decision makers.

This distortion affects accurate information on deaths and causes-of-death, which are indispensable for:	
Planning / funding	Health and community planning
	Identifying funding priorities
	Informing applications for development funding
Health	Monitoring the health of a population
	Planning for infant vaccinations and immunisation programmes
	Investment in prevention and early diagnosis for significant health issues (cancer, dialysis, heart issues, hereditary conditions)
	Evaluation of health treatments and programme impacts
Statistics and reporting	Access to real-time information on population size and structure
	Providing the necessary information for the calculation of all population-based development indicators used to track development progress
	Ability to match death notification with birth registration
Crime	Reducing identity theft and fraud

Sharing information alone is not enough - internal information collected through local BDM offices would need to be inclusive and accurate, for the imported information to add any value.

What information should be considered for sharing?

In order to address the under reporting of deaths, and causes of deaths occurring overseas, and some of the issues associated with diminished reporting ability for decision makers, the following data sets would need to be *considered* for potential information sharing.

Allow positive identification

    a. Name (First, surname)
    b. Sex / gender
    c. Date of birth
    d. Place of Birth (including country)
    e. First Name(s) of Mother
    f. Surname of Mother
    g. First Name of Father
    h. Surname of Father
    i. Registration Number
    j. Date of Registration.

Update birth records

    k. Date of death

    l. Place of death

Update name records (name change)

    m. New name

Provide valuable data for statistical analysis

    n. Cause(s) of death
    o. Occupation, profession or job

Data Matching

The New Zealand system allows a potential match of death and birth registration documents to be considered if key identifiers correspond exactly. A potential match could be considered if the records had any discrepancy, but would require further manual examination. To be confident for an exact match, the two registration documents must match exactly on:

Death Registration (NZ)	Birth Registration (Pacific Island)
Surname (at birth) of Deceased	Surname of child
First Name(s) (at birth) of Deceased	First Name(s) (at birth) of child
Date of birth	Date of birth
Place of birth (key word search)	Place of birth (key word search)
First Name(s) of Mother	First Name(s) of Mother
Surname(s) of Mother	Surname(s) of Mother
First name of Father	First name(s) of Father
Surname of Father	Surname of Father
Registration Number	Registration Number
Date of Registration	Date of Registration

Exact data matching would currently prove difficult due to variations in data quality and format of information collected for CRVS records in individual countries. e.g. fluidity of name, variation in what information is requested and lack of centralised systems.

Historical information

An electronic system was introduced in New Zealand for the recording of life events in 1998. The information recorded prior to this time is mainly managed either via an index (a reduced data set) or is still recorded on paper. Legislative changes over time have also impacted on what information is collected in relation to each life event.

Cause of Death information

NZ lifedata records a primary, plus up to 3 supplementary causes of death, based off the medical certificate or Coroner's Authorisation, resulting in each record being unique to the individual who has died.

This would not necessarily provide the detail to classify all deaths under the World Health Organisation's 'International Classification of Diseases' (ICD10) codes, which allow for the identification of health trends and statistics globally.

Do all BDM departments currently collect the same information?

In short, the answer is 'no' (See appendix 2). Ideally, not only would each country collect the same information, it would collect it in the same format. Although the wider UN and Brisbane Accord Group (BAG) work will focus on how accurate or complete the registry information is, the current lack of consistency between formats and data collected becomes one of the barriers to sharing information.

3. Barriers to information sharing

The barriers to sharing death and cause of death information between New Zealand and Pacific Island nations; include

Defining the population group for which information will be shared
Where the individual was **Born, ethnic group** or hold **resident** or **citizenship** status

Identifying / matching records
• Fluidity of identity (multiple spelling / changing name etc.)
• lack of common 'identification matching' protocols
• lack of common/consistent practices (data collected, storage etc.)
• Identity security (out of scope)

Data entry
• Inconsistency with naming protocol (place of birth etc.)
• Spelling inconsistencies
• Formatting inconsistencies

Data quality issues (out of scope)

Technology (IT systems, hardware etc.)

• Compatible records management systems and processes
  ○ Data format (paper/electronic / file type)
  ○ Data preservation issues (paper records deteriorating / electronic back-up etc.)
  ○ Compatible software

• Meeting requirements for the provision of data security

Legislation
• No specific legislation changes required for initial sharing of death information
• Consistent privacy protection laws might be required for possible future opportunities

Funding
• Identifying and accessing funding sources

4. Policy context and policy case for sharing information

Identifying opportunities and barriers to sharing information, particularly relating to death in another country is one of the work plan items in the Pacific Civil Registrars Network Terms of Reference.

The need for information sharing of 'death' and 'causes of death' has been identified as critical to the region.

Accurate statistics of births and deaths, and causes of death, would allow for much needed health and development planning in the Pacific region. It would also contribute to reducing the identity fraud risks, from birth records remaining open for deceased people.

Special relationship
New Zealand has relationships with Samoa, Cook Islands, Tokelau and Niue. See appendix 3 – nature of the special relationship.

In practice, the special relationships are based on historical events, geographical and cultural connections, and a shared willingness to work together.

Development context
CRVS systems across the Pacific region, including New Zealand, have limited capacity or capability to deliver all the benefits to decision makers of having accurate information on death and causes of death. Under reporting of death events, information accessibility and quality, common formats, and modern computer systems are but a few of the barriers.

Strategic decisions will need to be made to identify priority outcomes and funding opportunities, and how to best achieve the outcomes desired. There is no point in prioritising and funding an individual bespoke computerised system, until the processes that ensure quality information and the requirements needed for information sharing are first in place.

Plans can be developed to achieve the objectives, which may include; increasing percentage of death notifications received within each region, agreeing on a common set of data requirements and format, and potentially moving to a shared IT platform.

5. Legislative framework (Births, Deaths and Marriages)

There is provision in the Birth, Deaths, Marriages, and Relationships Registration Act 1995 (BDMRR Act 1995), for the Registrar General to share name change and death information under the following conditions and processes.

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s78D(1) – Registrar General may share name change and death information with foreign registration authorities relating to a person whose birth is registered in the State in which the foreign registration authority has jurisdiction.

Process:
s78E(1) – Supply of information to foreign registration authorities must be in accordance with written agreement

The supply of information under section s78E(2) must be in accordance with a written agreement between the Registrar General and the foreign registration authority concerned. The agreement must state:

a.   The purpose of the agreement
b.   The information that can be supplied
c.   The method by which, and the form in which, the information may be supplied
d.   How the foreign registration authority will use the information
e.   The fees (if any) payable for the supply of the information

S74E(4)The Registrar General must consult with the Privacy Commissioner before entering into or varying an agreement.

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6. Legislative framework (Privacy)

Under the BDMRR Act 1995, the NZ Registrar General must consult with the Privacy Commissioner (NZ) before entering into a new or changing an existing information sharing agreement.

The Privacy Commissioner will need to be assured that:
1.   the information being shared is for a valid reason
2.   an Information Sharing agreement (ISA) for the specific use of the information is agreed
3.   a technical appendix for the 'how, what and when', which could be amended separately to the main ISA document, is included

4. adequate measures are taken to secure any information being shared. This would include ensuring secure information sharing processes (ie. file encryption) is used.

7. Technical capability (IT, systems, resources)

Lack of technical support, appropriate hardware, common IT systems or architecture of CRVS systems across the region poses a number of challenges to sharing Information, and potentially undermines the opportunities that any sharing would achieve.

Where IT systems are either not functional or not integrated with established reporting protocol, and regional Information collected into a single electronic hub, regardless of information sharing will struggle to overcome the barriers of having large proportions of the birth population of the country unaccounted for, as described in section 2.

Hardware

Varying levels, or lack, of investment in IT infrastructure, has resulted in over reliance on old hardware and slow internet connections across the Pacific region.

CRVS System

CRVS systems (registries), across the Pacific region are at varying levels of sophistication, with each country having a bespoke and often aging system. Limited remote access and slow internet connection have resulted in ongoing problems with maintenance and support.

Day three of the Civil Registrars meeting has a presentation on the 'Innovations in Civil registration IT systems', which will be very relevant to this topic.

Opportunity

New Zealand's CRVS system is scheduled for a much needed 'upgrade', as like many other systems across the region it has become old and no longer fit for purpose. This presents an opportunity for member countries to 'piggy back' on New Zealand's upgrade, and possibly secure funding for a joint proposal.

8. Social Considerations

Significant challenges to information matching due to cultural aspects of identity and naming convention i.e. use of titles, customary adoption of names, legitimate spellings variations, and fluidity of identity, does not easily match the 'black and white' information matching protocols currently in practice in New Zealand.

Traditional BDM frameworks and especially information sharing relies on there being methodical, precise documentary requirements for proving identity and matching records. From a Pacific perspective, where formal identity can change as a person matures through there life, the BDM framework needs to be flexible enough to accommodate Pacific Island complexities, or find an alternative way of dealing with them.

9. Potential funding opportunities

There are multiple funding options available, depending on the exact agreement from member countries on what they want to achieve from sharing BDM information, and how they plan to use it. These include;

- The New Zealand Aid Programme has a range of funding and contracting opportunities to provide effective, sustainable aid in developing countries. These would allow us to draw on expertise and technical skills from New Zealand and elsewhere, to build capacity and skills in the region. http://www.aid.govt.nz/webfm_send/466

- The Pacific Security Fund (PSF), is available to New Zealand Government departments and agencies to undertake activities that will advance or protect New Zealand's security interests by reducing risks from threats arising in or operating through Pacific Island countries. Administered by the Ministry of Foreign Affairs and Trade (MFAT) the PSF allocation for 20014/15 is $2.7m.

- Funding opportunities would also exist within NGO organisations that are interested in a more cooperative / collective impact type approach.

10. Discussion and agreement on what PCRN and member countries should do next.

The Pacific Registrars Network has identified addressing information sharing between countries as a priority. However, key questions need to be addressed prior to considering information sharing between member's BDM registrars.

1. What **outcomes** do PCRN want to achieve (both short and longer term) from sharing 'cause of death' information for citizens who die in another country?
    a. What are the critical 'areas' current information is not delivering?
    b. Would better internal information (full and accurate collection of births and deaths within each country) offer more that adding 'shared' information?
    c. Are some regions more ready than others?
2. Identify need, and seek funding opportunities.
3. What focus should be placed on consistency across members BDM systems, rather than sharing information?
    a. Common forms
    b. common processes.
4. How will outcomes of information sharing be assessed?
5. What are the foundations that need to be in place prior to sharing information?
    a. IT

b. consistency
c. data management etc.
6. What are the implications of sharing Information?
   a. Privacy
   b. information protection
   c. resources, and technical ability.

Possible future opportunities

a. Potential for a common civil registry system, to enable easy transfer of death information for those dying away from their birth country, it would also streamlining citizenship and passport processes between the Cooks, Samoa, Niue and Tokelau, and mitigate some of the risks associated with small nations having to maintain their own infrastructure.
b. Expanding the group of nations sharing death and name change Information.

If we want to take this to the next stage we would need to consider	
Data quality	a. **Adopt** common '**Notification of death'** and other BDM forms b. Record data consistently (format).
IT - hardware / CRVS software	c. Conduct an assessment of current 'IT capability / capacity' across BDM offices d. Seek funding opportunities to ensure all BDM offices have access to the minimum standards of hardware needed e. Consider opportunities for member countries to use the same software package to maintain their BDM & name changes databases.
Information sharing	f. Define exactly the population cohort g. Draft an 'Information Sharing Agreement' for the principles of Information sharing.
Legislation	h. Conduct a high level privacy impact assessment.

Operational processes	i. Develop an operational / policies manual, that includes;
	    a. What happens if an error is made i.e. how to handle any disputes
	    b. Record matching protocol
	    c. Standard 'forms' and Information format management.