Aboriginal & Torres Strait Islander Suicide Evaluation Project

Real Time Suicide Data: A Discussion Paper

Professor Pat Dudgeon and Dr Yvonne Luxford

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The Aboriginal and Torres Strait Islander Suicide Prevention Evaluation Project (ATSISPEP) is an important Australian Government funded initiative to identify what programs and services are most effective in helping reduce high rates of suicide among Indigenous Australians. It is particularly important because suicide among Indigenous Australians has emerged in the past half century as a major cause of their premature mortality and a contributor to the overall health gap.

Indigenous suicide was almost unheard of prior to the 1960s. Yet in 2014 it was the fifth leading cause of death among Indigenous peoples and the age-standardised completed suicide rate was around twice as high as the non-Indigenous rate.

Critically, there has been no significant change between 1998 and 2012 in the formally recorded rates in NSW, Qld, WA, SA and the NT (where data is deemed reliable). From 2001 to 2010, about 100 Indigenous people died by suicide each year in Australia. Since then, the situation appears to be getting worse. In 2012, 117 Indigenous suicides were reported; in 2013 the number was 138; in 2014 it was 143.

This shows that Indigenous suicide rates are increasing. However, a small part of this increase might be due to improvements in data collection and reporting. More accurate data collection is a positive outcome of the significant and ongoing changes which have been made in recent times. However, data collection particularly real time data remains an important issue. There needs to be a focus from the growing number of Indigenous suicides and the need for multisectorial action on the collection and reporting of data.

Three main issues can be identified:

- 1. There is variable quality of Aboriginal and Torres Strait Islander identification at the State and national levels, resulting in an expected under-reporting of Aboriginal and Torres Strait Islander suicides.
- 2. Lack of reporting on suicide due to questions regarding intent, especially in the case of childhood suicides. Similarly, it can be demonstrated that there may be a reluctance to classify adult deaths as suicides for a variety of reasons also.
- 3. Delays in reporting data, whereby incidences of Aboriginal and Torres Strait Islander suicide might not be known for months and often years after the fact.

The delay between the timing of suicide events and their reporting is an impediment to the early detection of systematic trends (including 'suicide hotspots and clusters') and intervention responses aimed at preventing further suicides. Accessibility of real time data is an essential component in efforts to ensure that bereaved families and communities can access the services they need, and also to enable targeted interventions to prevent the development of suicide clusters.

Whilst the focus of this discussion paper is on the provision of real time data, all these issues interact to create inadequate data collection at this point in time.

Identification as Aboriginal and/or Torres Strait Islander

The Indigenous status of a deceased person is recorded on the Death Registration Form and/or the Medical Certificate of Causes of Death. The Australian Bureau of Statistics (ABS) states that it receives data for around 99% of all deaths which identify Indigenous status, but recognises that this still represents under-identification as the data may be inaccurate.- The ABS argues that propensity to identify as an Aboriginal and Torres Strait Islander is determined by a range of factors, including:

- how the information is collected (e.g. census, survey, or administrative data)
- who provides the information (e.g. the person in question, a relative, a health professional, or an official)

- the perception of why the information is required, and how it will be used
- educational programs about identifying as Aboriginal and Torres Strait Islander
 - cultural aspects and feelings associated with identifying as Aboriginal and Torres Strait Islander Australian.

Identification may also be complicated by an individual's past and their understanding or sense of acceptance of their Indigenous status. This may be particularly pronounced for members of the Stolen Generation and their children. Whilst some solutions are being developed to increase levels of identification, this needs to be undertaken in parallel with efforts to achieve universal levels of registration of birth. It is estimated that thousands of Indigenous Australians, alongside those of CALD backgrounds, have not had their birth registered, or do not have sufficient levels of identification to enable issuing of a birth certificate. This is not restricted to members of the Stolen Generation who may have had arbitrary dates of birth assigned to them on a mission, but also for many children born currently.

The ABS records indicate that 965 of deaths recorded in 2014 did not state whether or not an individual had Aboriginal and/or Torres Strait Islander status. In such cases the status is recorded as unknown. It should be noted that the National Coroners' Information System (NCIS) does not record ethnicity, only whether or not the deceased is of Aboriginal or Torres Strait Islander background.

Whilst this only represents 0.6% of deaths nationally, the issue is highlighted when one considers that the Queensland Suicide Register (QSR) demonstrates that from 1990–2006, 14.2% of suicide cases did not record any form of ethnicity, and this applied to 42.9% of cases prior to 1994. To counter this level of under-reporting, the QSR introduced a category of 'Unknown but not of Aboriginal or Torres Strait Islander', in addition to adding Asian as an ethnicity.

The Australian Institute of Health and Welfare (AIHW) draws attention to a further confounding factor that individuals responding to the question of Indigenous status may incorrectly interpret non-response as meaning non-Indigenous.⁻ This could apply to non-Indigenous people answering the question, or those interpreting non-responses, both of which effect the data interpretation.

Even though the question of cultural identity is a mandatory question for police attending deaths, there is little quality control to ensure that the question is asked. It is possible that police attending a suspected suicide may feel that asking too many apparently administrative questions furthers the distress of the relatives present. In an effort to improve identification, Victoria has introduced a process where Funeral Directors are required to ask 'the question: "Was the deceased of Aboriginal or Torres Strait Islander origin?" of every informant and/or the person who knew the deceased when completing a Death Registration Statement'.-

The ATSISPEP Data and Statistics Roundtable Consultation recommended that questions of cultural identity always be asked of the senior next of kin, and that appropriate education be provided to everyone asking the question to ensure that it is managed in a culturally safe manner.

It is due to the ongoing issues with identification that only data for New South Wales, Queensland, Western Australia, South Australia and the Northern Territory are included in the data cubes which form part of the ABS annual *Causes of Death* publication.

The problems associated with poor levels of identification are well recognised, and action is being taken across all jurisdictions to address the issues by seeking national consistency through the mechanism of the National Civil Registration and Statistics Improvement Committee (NCRSIC).

Classification of a death as Suicide

Before it can be registered, a death must be certified by a doctor using the Medical Certificate of Cause of Death, or by a coroner. Different requirements exist in different jurisdictions, but generally the requirement for certification by a coroner exists when:

- where the person died unexpectedly and the cause of death is unknown
- where the person died in a violent or unnatural manner
- where the person died during or as a result of an anaesthetic
- where the person was 'held in care' or in custody immediately before they died
- where the identity of the person who has died is unknown,-

hence a suspected suicide will require referral to a coroner. Of the 153,580 deaths recorded in Australia in 2014, 14% were reported to a coroner.-

The release of the Report of the Senate inquiry into suicide, *The Hidden Toll,* prompted ongoing national collaboration to improve the recording of data related to suicide, however, there remain many issues with the current data collection mechanisms. The current process is best explained using the following flow chart.



Australian Cause of Death Statistics System

The timing of the processing of death data by the ABS was one of the primary problems experienced in accurate data recording, in that a cut off period a little longer than a year after the reference year was used to ensure timely publication. As there was no revision of the data at a later time, significant numbers of deaths subject to coronial investigation missed the cut off date and were not recorded. As there was a rush by the NCIS and ABS to finalise data before the cut off date, data quality was also compromised. Both issues contributed to ongoing inaccurate and underreporting of suicides.

This issue is openly admitted by the ABS who state:

The quality of causes of death coding can be affected by changes in the way information is reported by certifiers, by lags in completion of coroner cases and the processing of the findings.

It is always possible that a death due to suicide is not reported to the coroner, either because it is genuinely not identified as a suicide at the time, such as an older person taking a poison and dying in a manner resembling a heart attack, or from a wish to protect community or distressed relatives.-

Even when a first responder may believe that a death is by suicide, a coroner is required to determine suicidal intent beyond all reasonable doubt, and may choose to be cautious in their determination and return an open verdict. Research has clearly ascribed a wish to protect relatives from distress as a reason for coroners choosing not to give a determination of suicide.- Different factors about the death have been demonstrated to influence a coroner's decision. Past psychiatric history, sharing an intent to die, and the method used all influence this decision making-, with modes of death such as drowning, poisoning, jumping and self-immolation shown to be less likely to be determined as a suicide.- Researchers argue that the majority of open verdicts are actually suicides, with those that are not being quite obvious, such as deaths of babies.-

Canadian research into the validity of coronial decisions has revealed that deaths from heroin, over-the-counter medication, and injuries from jumping had a less likely probability of being correctly certified.⁻ This again emphasises that coronial decisions as the sole source of suicide data is fraught and likely to lead to underestimation of deaths by suicide.

Similar research in England has demonstrated that coroner's likelihood to ascribe suicide to a death fluctuates over time, often accompanying increased use of 'death by misadventure or accident', especially in the case of poisonings.-

The legislation within which a coroner operates may also influence their determination of intent. The *South Australia Coroners Act 2003* only requires that a coroner 'ascertain the cause or circumstances' of a death where an inquest is held.- Coroners interpret this to mean that they are restricted from declaring circumstances of death, i.e. intent to complete suicide, in any case which does not go to an inquest. Instead, government clerks complete the forms without input from the coroner.-

Coroners exist within the same sociocultural influences as everyone else. It has been suggested that their verdicts may be influenced by factors such as having differing levels of education, different exposure to medical/legal examinations and autopsies, different personal definitions of suicide, and religious and cultural contexts. A recent re-examination of cases in France found that 35% of those said to be 'undetermined' and 25% of those said to be from 'unknown causes' were reclassified as suicides.- In Britain, growing use by coroners of a narrative verdict has further confused the issue of intent and is leading to increasing underestimation of the true rates of suicides.- Similarly, coroners who give more verdicts of cause of death as 'other' are less likely to pronounce death as being caused by suicide, which can cause considerable skewing of data in small regions.-

With 29% of coroners' verdicts nationally omitting reference to intent, coding of a death as due to intentional self harm may fall to the NCIS. When this occurs, care is taken to focus on methods strongly indicative of suicide such as hanging, motor vehicle exhaust and plastic bag asphyxia.--

Real time data

Recognition of the need for real time suicide data is not exclusive to Australia. The comprehensive survey, *Suicide in Ireland: 2003 - 2008* established a key priority:

Ireland needs a national real-time database for teen and young adult suicide deaths to facilitate the early detection of evolving clusters. Such a complete system is not currently in place, so the monitoring system default mode is either one of partial knowledge or one of catch-up – a model which confounds comprehensive planning and response.

The U.S. has similarly identified the need for faster access to data:

Efforts to track suicide in populations are hampered by difficulties in data collection. At present, lag times for reporting are three years for data in the United States through the Centers of Disease Control and five years or more for the World Health Organization. In contrast, social or economic conditions affecting the suicide rate may shift rapidly. Critically, some of these protective or predisposing factors may also be modifiable. However, using current methods, by the time a trend is associated with elevated suicide risk, it may have already peaked and waned, thereby closing the window for intervention.-

Despite efforts by the ABS, NCIS and interjurisdictional groups, reliance on coronial closure of cases can severely delay the collection of data related to suicides. Whilst related to data prior to the ABS revision of processes, there is no reason to suspect that the graph below demonstrating the delay from death to coronial decision is not as relevant today as it was a decade ago.



Efforts to improve the quality of data recorded in ABS suicide data have been significant, with a revision process now being established.

An issue for the ABS Causes of Death collection has been that the specificity of coding of causes can be affected by the length of time required for the coronial process to be finalised and the coroner case closed. Up to and including deaths registered in 2005, ABS Causes of Death processing was finalised at a point in time. At this point, not all coroners' cases had been investigated, the case closed and relevant information loaded into the National Coroners Information System (NCIS). The coronial process can take several years if an inquest is being held or complex investigations are being undertaken. In these instances, the cases remain open on the

NCIS. Coroners' cases that have not been closed can impact on data quality as less specific ICD codes often need to be applied in the absence of a coroner's finding.

To improve the quality of ICD coding, all coroner certified deaths registered after 1 January 2006 are now subject to a revisions process. If the case remains open on the NCIS, the ABS will investigate and use additional information from police reports, toxicology reports, autopsy reports and coroners' findings to assign a more specific cause of death to these open cases. The use of this additional information at either 12 or 24 months after initial processing increases the specificity of the assigned ICD-10 codes over time. As 12 or 24 months have passed since initial processing, many Coronial cases will be closed, with the coroner having determined the underlying cause of death and allowing the ABS to code a more specific cause of death. Different mechanisms have been suggested to provide data that will enable quick and effective action to prevent further suicides occurring.-

Impacts of changes to administrative systems

Since 2007, the ABS has invested in a revisions program for coronial data which allows additional time for cases to be investigated and determinations on the mechanism and intent of the death to be made. Revisions occur over the two years following the release of preliminary data. Coding practices have also been improved to allow coders to use information available on the National Coronial Information System (NCIS) to apply a preliminary code to open coronial cases. Since the introduction of the revisions process the number of deaths coded to intentional self-harm has been lower for preliminary data, and has increased in releases of revised and final data.—

In response to rapid spread of novel means of suicide such as charcoal burnings in Taiwan and helium inhalation in Britain (where deaths multiplied 17 times in a decade), a team in Yorkshire, England posited reports from HAZMED team attendance at deaths as a source of data. Such a data source will only have relevance where there is an appropriate team in place, and the cause of death is related to chemicals rather than hanging or firearms. However, it was demonstrated that suicide data was available in near to real time, and public health interventions could be reliably based upon this data to save lives.-

Another potential mechanism to track suicide is through social media. The Critical Response Project (CRP) already utilises small scale monitoring of Facebook posts to identify new suicide incidents amongst Aboriginal and Torres Strait Islander peoples in WA. At this point in time this process is limited to personal online connections of the CRP team due to the size of the project, although capacity for expansion of this aspect may be valuable.

Given that it had been established that internet search queries related to influenza closely mimicked the spread of the disease seasonally, researchers sought to establish whether internet use through Twitter posts demonstrated spread of H1N1 or swine flu. They found that tweets could be tracked to demonstrate public interest and concern about the virus, but also 'to estimate disease activity in real time'. This cannot provide predictions of activity, but enables real time data to be collected and acted upon immediately.

Internet search data has also been shown to reflect self harm and suicide rates, but caution is needed when interpreting this across differing age groups."

Perhaps a similar tracking methodology could be adapted to provide real time data regarding suicides. Tracking of 1,659,274 in the Mid Western U.S. over a three month period demonstrated a close geographic correlation between suicide related tweets and actual suicide data. The researchers concluded that 'Twitter may be a viable tool for real-time monitoring of suicide risk factors on a large scale. This study demonstrates that individuals who are at risk for suicide may be detected through social media'.- Could it be equally possible to track suicides via Twitter as a mechanism to identify potential cluster development? It may be possible to utilise this tool both

as a prevention mechanism to identify individuals or communities at risk of suicide, and as a mechanism to identify locations for a postvention focus.

Arguments have also been raised that the attribution of a death to suicide should be determined clinically rather than legally by the coroner. This would expedite the availability of data, and may significantly reduce under reporting. A comparison of clinical determinations of suicide in Galway, Ireland with determinations by coroners revealed a discrepancy of 300% when extrapolated across the country.

In addition to work being undertaken in Queensland and Victoria referred to above, further research is also a focus for the WA government. The WA Coronial Suicide Information System (WACSIS) is funded by Western Australian Mental Health Commission and includes the Western Australian State Coroner's Office, Western Australian Police Service, Telethon Kids Institute and the Mental Health Commission.

The system is designed to include data from 1986 to present day from Coronial electronic transfer files (to the National Coronial Information System) as well as data coded from free text files including autopsy results, police reports, toxicology reports, etc. resulting in a comprehensive and easily accessible collection of information on all suicides in Western Australia.

It is envisaged that this will enable early detection and communication of systemic trends for suicide in Western Australia in real time; and will provide more in-depth understanding of suicide in WA so as to better develop strategies for prevention.

Telethon Kids Institute maintained the Coroners' database on suicide up until 2010 with funding from the Mental Health Commission. This dataset contains data on completed suicide deaths from 1986 to 2008 and this dataset has also been linked to the Mental Health Information System and Hospital Morbidity Records. Since 2010, significant changes have occurred in data collection at the Coroners' Office and the advent of the case management system administered by the National Coronial Information System (NCIS).

The WACSIS will use NCIS core fields as base information and will include coded data from current free text files that reflect psychosocial, behavioural and demographic information on a wide range of demographic, psychosocial, psychiatric, medical, contextual and behavioural aspects of suicide cases and include information derived from police reports, suicide notes, post mortem and toxicology reports. This coding will allow the capturing of information in a state to allow for timely comprehensive analysis of all the circumstances surrounding suicide in Western Australia. This data source can be linked (with the appropriate approvals) to other administrative datasets such as midwives, mental health information system, hospital morbidity, child protection, police services, corrective services etc.

Conclusion

Without comprehensive, meaningful, timely and accessible data, all jurisdictions lack a clear understanding of the scope of suicide behaviours and hence, and the ability to take appropriate and targeted action in preventing suicides. It is also imperative that policies aimed at preventing suicide are developed based on good quality information and evidence. The design and implementation of effective preventive measures will be greatly enhanced by timely information on the characteristics of those who have suicided and the identification of possible current causative influences in specific populations in each state and territory.

There is no doubt that work to improve the speed of availability of data, and its quality is being actively pursued locally and internationally. One can't underestimate this effort – if timely knowledge of a suicide saves just one further life, its value cannot be denied.

It may be that the most beneficial mechanism to establish best practice will be to combine different approaches. The positive potential of the use of social media as a monitoring tool could be combined with the comprehensive data collection being established by the WACSIS. Clear protocols would be required to ensure identification of suicides of Aboriginal and Torres Strait Islander peoples, and what action would then be taken,

and by which agency or service to prevent further self harm in that community. A successful trial in WA could then be replicated nationally, perhaps utilising the Australian Health Ministers' Council.

From the viewpoint of suicide of Aboriginal and Torres Strait Islander people – both for the loved ones of those left behind, and those who can be protected – effort to improve real time reporting of suicide data must be maintained.

It is essential that:

- Coronial decisions are clear on intention, and delivered in a timely manner;
- Alternative mechanisms for data collection are explored, such as social media, funeral directors, etc.;
- The ABS and NCIS continue to monitor and improve their processes;
- National standardisation be reached on determination and reporting of suicide; and
- Aboriginal and Torres Strait Islander people be engaged to assist in ensuring that there are improvements in identification as Indigenous Australians, and that non-Indigenous Australians approach all deaths in a culturally sensitive and appropriate manner.

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