

## Towards systematic data collection and referral pathways for Indigenous youth suicide attempts

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### Abstract

Suicide is now a significant contributor towards Indigenous premature mortality in Australia. There have also been an increasing number of anecdotal reports of child and youth suicides and suicide attempts across Central Australia. However, no systematic protocol or database exists to collect information on attempted suicides in the region. As a result, suicide attempt data are collected in an ad hoc manner and methods and classifications vary between organisations. Suicide and other suicidal behaviour among Aboriginal peoples is often the outcome of complex and multilayered factors, and suicide responses have often focused on crisis response or postvention activities. It is essential that evidence based approaches to Aboriginal youth suicide are developed. Capturing accurate data on suicide and suicide attempts will provide a better understanding of the issue and enable the development of targeted interventions.

The aims of this project were to develop a systematic data collection system for Indigenous youth suicide and suicide attempts, and suggest appropriate referral pathways between agencies in Central Australia when a young person is assessed at risk of suicide. The latter aim was to achieve a more systematic approach to the provision of preventative interventions to individuals and their families. This project has been undertaken with the support of an Aboriginal Advisory Group, and ethics approval from two Ethics Committees. Twenty-two in-depth interviews were conducted with a range of practitioners from related areas (such as primary health, community support, youth services). Data were analysed using cross-case and thematic methods involving four researchers.

In this paper we report on the issues raised by individuals in achieving the stated aims, including:

- diversity of client data systems across agencies and within government departments; and inconsistent definitions of 'Indigenous', 'youth' and 'suicide'
- confidentiality; and fear of labelling clients
- difficulties in identifying young people at risk; and a perception of an inability to provide support for those individuals
- problematic criteria for access to services
- lack of confidence of staff to respond and recognise at risk clients
- cultural issues confronted by practitioners.

Possible ways of managing these issues are also proposed. In similar settings overseas, such as Canada, data collection systems have been developed which have required working through many similar issues. In reporting the themes raised by practitioners in Central Australia, we provide a basis for progressing the aims of the project locally and potentially further afield.

## Introduction

Suicide has become a significant contributor to Indigenous\* premature mortality in Australia.<sup>1-3</sup> Of recent concern has been the high and increasing rate of suicide and suicide attempts among young Indigenous peoples.<sup>4-6</sup> In the Northern Territory (NT), suicides have occurred in younger age groups among Aboriginal peoples compared to non-Aboriginal peoples<sup>6</sup>, with the rate of suicides for Aboriginal children under the age of 15 years (in 2001-2006) five times the overall Australian rate.<sup>7</sup> Considerable media coverage on the issue (see for example<sup>8-11</sup>) and an increasing number of anecdotal reports of child and youth suicides and suicide attempts (particularly in the Central Australian region) has brought the issue into sharp focus.

Suicides and other suicidal behaviour among Aboriginal peoples are often the outcome of complex and multilayered factors and not simply an expression of mental illness.<sup>12-14</sup> Various and combined methods of intervention are required to successfully address suicide, although in the past have generally focused on crisis response or postvention activities.<sup>15</sup> Approaches have shifted more to prevention and early intervention in recent years with a greater emphasis on the importance of holistic models and the social determinants of health, including environmental, socio-cultural, historical and economic factors.<sup>12,16</sup> A considerable proportion of completed suicides are associated with previous suicide attempts or self-harming behaviour<sup>17-19</sup> and thus sufficient information on these events should play a part in informing the development of localised suicide prevention strategies. The literature highlights the need to plan and coordinate prevention activities on a local/regional basis and that effective coordination and integration of community service responses and capacity building requires the development of explicit strategies.<sup>20</sup>

An NT Parliamentary inquiry into Youth Suicides in the Northern Territory in 2011 reported successful work being undertaken in the area of suicide prevention, however, generally Aboriginal suicide and suicide attempts among young people remain under-reported and poorly understood.<sup>6</sup> Importantly, the inquiry found no standard framework in the NT to collect information on suicide attempts or to inform appropriate coordination mechanisms between agencies, with many young people falling through the gaps and not getting the help they need. Lack of reliable and accessible information about levels of self-harm hinders understanding of, and ability to respond to, the problem and the evaluation of such responses.<sup>6</sup>

The primary source of data on suicide deaths are Coroners' offices, as a coroner is the only entity that can legally determine intent and certify a death as a suicide.<sup>6</sup> Coroners are required to certify deaths as suicide before data are input into the National Coroners Information System (NCIS), which is then fed to the ABS for coding, analysis and publishing.<sup>21</sup> However, no systematic protocol or database exists to collect information on attempted suicides in the region.<sup>6</sup> As a result, suicide attempt data are collected in an ad hoc manner and methods and classifications vary between organisations. Data collection procedures and reliability across the states and territories also vary considerably. The ABS does not currently report suicide for people under 15 years of age, since cases of suicide for these age groups were extremely rare in the past.<sup>4</sup> It is essential that evidence based approaches to Aboriginal youth suicide are developed. Capturing accurate data on suicide and suicide attempts will provide a better understanding of the issue and enable the development of targeted interventions.

This paper reports on a study undertaken in Alice Springs in 2012. The project team worked in partnership with the Life Promotion Program (LPP)<sup>†</sup>, with funding from the NT Government's Alice Transformation Plan. The aims were to develop a systematic data collection system for Indigenous

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\*The terms Indigenous and Aboriginal are used interchangeably in this paper. However, we recognise that in general, the term Indigenous is inclusive of all Australian Aboriginal and Torres Strait Islander peoples whereas Aboriginal is often used to refer to regional groups.

† LPP operates under the auspices of the Mental Health Association of Central Australia (MHACA), receiving targeting suicide prevention funding from both NT and Commonwealth governments. Role includes suicide prevention training and coordination of postvention responses.

youth suicide and suicide attempts, and suggest appropriate referral pathways between agencies in Central Australia when a young person is assessed at risk of suicide, with the ultimate goal of achieving a more systematic approach to the provision of preventative interventions to individuals and their families.

## Method

This qualitative study had the support of the LPP Steering Committee, and an Aboriginal Advisory Group to the LPP. The latter was consulted early in the project to ensure its local and cultural relevance. Ethics approval was obtained from two Human Research Ethics Committees. The method involved 22 in-depth interviews conducted by four researchers. The semi-structured interview schedule covered Indigenous youth suicide/suicide attempts and referral procedures (including current and preferred systems, definitions, barriers and challenges, and appropriate responses). Both the LPP Steering Committee and the LPP Aboriginal Advisory group provided advice as to who should be invited to participate. An Aboriginal researcher<sup>‡</sup> was available for cultural consultation and advice throughout the study.

Interview participants had various roles in Central Australia, both clinical and non-clinical, and were drawn from areas such as primary health, community support, education, police and youth services to ensure that a range of perspectives was represented. Both Aboriginal and non-Aboriginal participants were interviewed, and varied in relation to age, gender, education, qualifications, duration of time in Central Australia, and levels of experience and knowledge about suicide. Participants were interviewed as individuals and not as representatives of their employing organisations. We have taken care to ensure that no information used could identify individual participants, and a code is used in the results to represent participant quotes. In most cases, interviews were audio-taped and transcribed verbatim. A small number were hand-scribed according to the preference of the participant. Data were analysed using cross-case and thematic methods involving the same four researchers who conducted the interviews.

## Findings

In this section we report some of the key themes evident from the analysis. Issues concerning data collection were closely related to issues concerning referral pathways and are thus reported together.

The difficulty of collecting data and then appropriately referring Aboriginal youth at risk of suicide was found to be compounded by a lack of clarity in defining matters of identity, age, service criteria, policies on sharing information as well as differing data collection systems. Data collection was found to be specific to the needs of individual organisations, sometimes duplicated and often not actioned or accessed in any useful way. Many different data bases/systems were found to exist (different systems are used even *within* the relevant government departments). The high rates of staff turnover throughout the region was also said to contribute to data collection problems, and caused difficulties in building and maintaining the necessary system relationships to ensure good referral practices.

Defining Aboriginal youth was in itself problematic with different services using different age categories, and different understandings of Aboriginality. Age definitions used by various agencies included 10-25, 10-19, 12-18, and 15-24 years. Hospital paediatrics treats children and young people to the age of 14. Participants recognised that Aboriginal community members had differing definitions of youth related to cultural milestones, and that age limits were often not appropriate for dealing with Aboriginal young people and their families. Some examples were offered where practitioners felt obliged to continue to deal with individuals who were technically outside their own organisation's official criteria. Several participants pointed to examples of 10-13 year olds making threats and experiencing suicidal ideation with concern that this group may be overlooked in the service system. Many participants recognised

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<sup>‡</sup>From the Poche Centre for Indigenous Health (PCIH) in Alice Springs

there had been an increase in the use of suicidal threats by Aboriginal youth, but also agreed that even 'suicidal talk' should be flagged as a potential suicide risk. For example:

"...anybody who mentions it, even once. Even if they go 'I'm going to kill myself, no, only joking'. We would flag at risk" (P4).

However, there was inconsistency around whether incidents such as these would be recognised similarly between different agencies and between different practitioners. Some suggested that a suicide attempt is harder to define than suicide. For example:

"We spent a long time...talking about the definition of suicide attempt...it's about the person's intention to die, or was it accidental..." (P13)

Some individual workers were reluctant to label an event as a possible suicide attempt, fearing that this label would 'stick' (or be unable to be changed in databases) even after more in-depth assessment suggested otherwise. While some participants were genuinely concerned about this, others were adamant that any indication of suicide risk needed to be acted upon:

"There is a reluctance for us to label, when really we should label until it's shown otherwise" (P3).

A strong perception of an inability for the service system to provide support for young people thought to be at risk of suicide was evident in the interview data. Some of the obvious agencies that should be involved in working with young people at risk and their families were seen to be struggling:

"[they are] so overwhelmed and so appallingly resourced that you're reluctant to involve them for fear that it actually has negative consequences." (P5)

Several participants gave examples of efforts to engage other services only to find a lack of responsiveness or significant delay in response. For example, "I have called the mental health hotline in the past but have not ... found them to be reliant." (P4). Getting an 'out of hours' response was also difficult:

"...a lot of people are really frustrated with using the 000 number...There can be a pretty big lapse of time between somebody saying they're going to do something dangerous and anybody being around to help...". (P8)

The need for a central point for 'client information' was strongly identified. This need was especially relevant in the geographical area of Central Australia where "youth move around between communities so much, especially when in distress." (P8). Information that was "sharable"(and accessible) would enable resources and supports to be focused on the individual and would minimise duplication of effort.

However, despite a strong degree of willingness to move towards such a system, concerns about information sharing between organisations (related to confidentiality) and historical mistrusts were identified as major barriers to developing both a reliable data collection system and an effective referral pathway. Remote community health clinics, for example, were not always seen as a safe option for sharing detailed referral information with because of historical levels of mistrust by some Aboriginal youth and their families.

The lack of clarity about "what to do [and what is done] with information obtained from family and community members" (P6) was a barrier in some organisations engaging at a system-wide level, but one that could be overcome with appropriate training and on-going support for staff within relevant organisations. Some participants pointed to their own and others' efforts in raising awareness of the problem of accessible data and a responsive and coordinated service system response. For example:

"If I know about something, who do I pass it on to? And what I've been doing lately is telling [the relevant services], 'You need to speak to so and so. I've heard from family that this person's

struggling’...[T]here’s no central place...we should have a central office, someone ... that looks after mental health wellbeing and networking...” (P6).

There are many accounts of problematic criteria for access to services. This is the result of agency policies having limitations on criteria for who they can work with and how, and it can also be the result of an underlying reluctance on the part of agencies to work collaboratively or in a ‘shared’ capacity. For example, the data indicated the existence of a ‘demarcation’ that is sometimes made once a client is assessed as being at risk of suicide. If a young person’s assessment places them in the health care system under a mental health category, there was evidence this has led to a ‘hands off response’ from other service providers.

A related issue is the lack of clarity about who should take the lead in working with clients, how that decision should be made, and by whom. Without that level of confidence in the service system, problems of access and coordination are inevitable.

“...referral models must enable a rapid response that provides an effective presence where it is needed. Responsibility must be clearly defined. There is no time for arguing over service boundaries or who is available at the time.” (P10)

In general, there was strong agreement that the current system deals inadequately with Indigenous young people at risk of suicide:

“We start hearing from the Police that they were clearly at risk. So something’s falling down. They’re not getting referred to Mental Health or the Health Clinics ...or Congress Social Emotional Wellbeing, or [the Emergency Department]....there are all sorts of reasons why the referral system doesn’t work.” (P13)

The problem of a perception of overstretched and/or unresponsive services was a major barrier to good system responses to youth suicide risk. However, there was also a belief that some services did not have the required skill levels or resources to be helpful. This included a lack of confidence of staff in some agencies to respond and recognise at-risk clients. For example:

“There can be the opinion of ‘they don’t really mean it’ or ‘they’re just saying that’ or something like that, so there’s no importance placed on what they’ve said.” (P20).

Finally, there were many cultural issues confronted by practitioners. Not surprisingly, this was multifaceted, but a lack of confidence in accurately assessing and responding to suicide risk from a cross cultural perspective was implicated in underreporting, and inappropriate or non-existent referral of youth at risk of suicide.

“... and then you’ve got the constant rotations in of new staff from cities, from a whole realm of other jurisdictions that don’t have the contextual knowledge of what’s going on here.” (P20).

“...[remote health clinic staff] also find ‘...it difficult to provide that support...they haven’t got the information for awareness...how to deal with these people when they come into the clinic.” (P6).

Some participants felt there was no shared vocabulary to discuss suicide issues in an intercultural context which could contribute to inadequate and inaccurate risk identification, data collection and referral decisions. Professional development as a way to counter many of the barriers to the effective identification and referral of Indigenous youth at risk of suicide (including cultural differences in understanding the issue) was an additional theme arising from the data analysis.

## Discussion

There is no current systematic approach to identifying and managing Aboriginal youth at risk of suicide in the Central Australian region, with poor understanding of the extent of the problem and effective

responses. The major themes arising in the data, which have acted as barriers to developing an effective approach, can be summarised as:

- diversity of client data systems across agencies and within government departments; and inconsistent definitions of 'Indigenous', 'youth' and 'suicide'
- confidentiality; and fear of labelling clients
- difficulties in identifying young people at risk; and a perception of an inability to provide support for those individuals
- problematic criteria for service access
- lack of confidence of staff to respond and recognise at-risk clients
- cultural issues confronted by practitioners, particularly those relating to intercultural communication and assessment.

A lack of reliable and accessible information about levels of self-harm and suicide ideation has hindered understanding of the problem of Aboriginal youth suicide, and thus the ability to both respond to, and evaluate, suicide prevention initiatives.<sup>6</sup> Development of a system of data collection for this purpose requires definitional problems to be addressed as well as the development of culturally acceptable categories. For example, restricting 'youth' to the World Health Organisation consensus of 15-24 does not allow for different cultural definitions<sup>14</sup> and ignores trends in suicide ideation in younger age groups increasingly observed by practitioners in this study. Models overseas have successfully developed local tools with a high level of cultural acceptability.<sup>22</sup> Although individual agencies will continue to have specific data requirements (such as for reporting to funding bodies and/or to inform their own practice), the will exists for a separate (or additional) locally-specific data system that allows for broader definitions and which will contribute to a much needed knowledge base. This may amount to more administrative work in the short term for some agencies, but will contribute to more efficient service provision in the longer term.

Such a system will also need to ensure that reports of attempted suicides from different sources do not result in multiple counts of one event, and clearly distinguishes between attempted suicide, suicide threats, and 'self-inflicted' accidents resulting in hospitalisation.<sup>6</sup> This will require the identity of the person to be recorded accurately (and protected by confidentiality). However, relaxing confidentiality requirements for the purposes of better suicide prevention was a strong theme in the NT Parliamentary inquiry<sup>6</sup> and was also a theme in the current study. Again, the will exists amongst agencies to design a local system that will meet these requirements. In seeking to coordinate the collection of suicide attempt data, there needs to be agreement not only on a data template, but also which organisation will act as the central repository and how any data collected will be accessed and used, including by contributing organisations.

The issues of data collection and the development of referral pathways are inextricably linked, and both will require high levels of coordination in the Central Australian region. The 2011 NT inquiry recommended establishing mandatory procedures to provide follow up support to young people who have been in psychiatric care, have been treated following an attempted suicide, or who are assessed as being at risk of suicide; actioning of protocols between police, correctional facilities, hospitals, mental health services, telephone crisis support services and community organisations was also recommended.<sup>6</sup> Data from the current study clearly highlighted the uncertainty about which individuals and services should take carriage of coordinating the response when someone is identified 'at-risk', and found no existing systematic mechanism for making such a decision.

Large regional variations in the level of service coordination and cooperation<sup>6</sup> as well as variations in what is deemed locally and culturally appropriate in suicide responses<sup>15</sup>, points to the need for a locally-

specific system. There have been successful attempts to develop similar systems of risk management, data collection and referral overseas.<sup>22,23</sup> While it is not possible to simply duplicate these models, the processes of their development provide important lessons. The extensive processes of consultation, partnership development and trust-building that underpinned the development of these models are fundamental requirements for any similar initiative.

## Conclusion

The results of this study have led to the development of a suicide risk form (data collection template) and a referral pathway model for trial use among various stakeholders in Central Australia. The trial of these resources, to occur in 2013, will form part of a second stage of research that will use an action research approach for further development and implementation, including reaching agreement about coordination roles. Outcomes of the proposed action research process will be reported in subsequent phases.

Findings to date highlight multiple and complex factors influencing the accurate collection of suicide and suicide attempt data, and the development of an agreed referral pathways model for Indigenous young people at risk of suicide. Overwhelmingly, the data support the development of a process to ensure accurate identification of these events with a strong (possibly mandated) protocol for referral and coordination, supported with appropriate training and resources. In reporting the themes raised by practitioners in Central Australia, we hope to provide a basis for progressing the aims of the project locally and potentially further afield.

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