

Ms Melanie Gibbons MP
Chair, Committee on Children and Young People
Parliament of New South Wales
6 Macquarie Street, Sydney NSW 2000

By email: childrenyoungpeople@parliament.nsw.gov.au

Dear Chair

# **Inquiry into Prevention of Youth Suicide in New South Wales**

I refer to my recent appearance at the Committee's Inquiry into Prevention of Youth Suicide in New South Wales, and specifically to the question taken on notice, from the Hon. Greg Donnelly:

"In looking at data in Australia to endeavour to make some sense of trends, if one can, what would you say we can take as a starting point, going back in history, when we have quite good data, quality data, with respect to youth suicide?"

Please find attached my response to the question.

If you require any further information, please do not hesitate to contact Ms Julie Zieth, Executive Officer, on

Yours sincerely

Catherine Lourey

NSW Mental Health Commissioner

OS March 2018



The Commission is not the collector of the data, and provides the below advice from the Australian Bureau of Statistics (ABS), representatives of which also appeared at the Inquiry.

- 1. The ABS employs two strategies to enhance the quality of data on intentional self-harm: open coding where contextual information on a death is accessed prior to a case being officially closed by a coroner; and a revisions process where open cases are revisited over a two year period to ensure additional information made available since initial coding is taken into account.
- 2. The ABS has always conducted an open coding process. However, it is acknowledged that the quality of open coding is dependent on the availability of key reports (police, autopsy, toxicology and coroners reports) on the National Coronial Information System (NCIS). The availability of information differs between State and Territories. The NCIS regularly liaises with Coronial courts on quality and timeliness of information, and there have been notable improvements in the timeliness of report attachments over the last five years.
- 3. The revisions process has been applied to data from 2006 data onwards, and was implemented in response to concerns of an undercount in suicide numbers at that time. In the year 2000, the ABS began using the NCIS as the single source of information on deaths referred to a coroner (as opposed to dealing directly with Coroners courts), but for some deaths the assignment of underlying cause was hindered by insufficient information being available at the time of coding. It is acknowledged that this resulted in a likely undercount of suicide deaths in published data between 2001 and 2005.
- 4. The combination of the revisions process and open coding have proven successful in addressing quality concerns with counts of suicide deaths. While continuous improvements in processes have led to much more complete counts of suicide deaths in 'preliminary data' (the first release of data prior to the revisions process being conducted), the comparability of time series based on 'final data' (that which has been through the 3 year revisions process) is strong from 2006 onwards.
- 5. In recent years the ABS has also improved its recording of other conditions associated with suicide deaths. For a death of a young person this means that mental health conditions such as depression or suicidal ideation are more likely to be recorded as part of the ICD coding process. These conditions are assigned to all deaths when reported, regardless of intent (i.e. accident, suicide, assault), providing important contextual information relating to deaths of young persons.
- 6. While the historical quality of national data on suicide has been carefully examined at a population level, it has not been specifically examined for youth suicide. Quality issues relating to suicide deaths of children and young people may differ to those for people at other ages.



"In looking at data in Australia to endeavour to make some sense of trends, if one can, what would you say we can take as a starting point, going back in history, when we have quite good data, quality data, with respect to youth suicide?"

Consistent with Action 3.4.6 of *Living Well: A Strategic Plan for Mental Health in NSW 2014-2024*, the Commission has been exploring the merits of a suicide prevention intelligence system for NSW as quality data to guide suicide prevention activities has been lacking across all populations, not only youth suicide.

As part of this work, the Commission has

- consulted with other states regarding their current approaches (summary attached in Appendix A)
- had detailed discussions with relevant government agencies, in particular NSW Ministry of Health and the Coroner's Office
- commissioned research undertaking a qualitative analysis of coronial investigations in suspected and determined intentional deaths
- considered the current context of suicide prevention initiatives at both the Commonwealth and state level.

It is important to gather data on attempted suicides and suicides to inform suicide prevention activities. Currently in NSW, data on attempted suicides is collected by hospitals in Local Health Districts and coded as 'intentional self-harm'. The NSW Ministry of Health is the custodian of this data. Suicide deaths data is collected from Coronial reports and recorded on the National Coronial Information System (NCIS). The Australian Bureau of Statistics (ABS) uses NCIS data and it is generally agreed that improvements to data collection processes have increased the quality of data since 2006.

# **Current Opportunities to enhance data for NSW**

Stakeholders have expressed a consensus view that in NSW there is currently a critical gap in terms of a systemic commitment to having a robust data set, such as that offered through a suicide prevention intelligence system, to improve our understanding of and response to suicides in NSW.

In order to find the best solution for NSW, the Commission suggests two possible ways forward:

- (1) To explore and analyse available models to develop a new system from the ground up, including identifying an appropriate research partner to scope a proposal and model its potential impact. This would involve efforts to work through the following issues:
  - confirming the best sets of data to include in a register held by the Ministry of Health and other organisations
  - which agency is the appropriate host for the suicide prevention intelligence system
  - whether legislative amendment is required to support the permanent establishment of a suicide prevention intelligence system in NSW (e.g. similar to NSW Cancer Registry)
  - the resolution of data linkage and privacy issues



- what costs would be involved over the long term to maintain a suicide prevention intelligence system, and which agencies would meet these costs
- improving data quality, particularly from first responder agencies.
- (2) Through the *LifeSpan* trials, the equivalent of a suicide prevention intelligence system has been established in each of the four trial sites. This data work is a substantial enhancement to the comparative suicide register models in other states and territories as it has more advanced data linkage protocols, sources and analytical capabilities and if developed statewide would ensure that NSW is best placed to have robust data to inform and support its policies and programs in relation to suicide prevention.

There are a number of potential benefits to scaling up this approach across NSW including:

- *LifeSpan* is being run by the Black Dog Institute which is a recognised world leader in the space of suicide prevention
- maximising the benefit to the state by building on the philanthropic and private investment into the *LifeSpan* trials, in particular:
  - reduced cost to the state due to utilising the existing personnel, skill, and data already held within the LifeSpan project
  - reduced time to establishment by building from existing work
- there may also be a potential to establish this initially as a research project under existing
  ethics approval while medium and longer term considerations are worked through with
  stakeholders.

In the short-term the main potential barriers to scaling up the *LifeSpan* trial site data registries to become a statewide suicide prevention intelligence system are the renegotiation of data sharing protocols and securing the support of contributing agencies.



#### Appendix A: Interstate Approaches in relation to Suicide Data

#### Victorian model

- In 2008, following the Black Friday fires, the role of the coroner was explicitly expanded to include a role in prevention. A specific prevention unit was then established to assist coroners to make appropriate recommendations from considering systemic issues emerging from particular classes of deaths subject to coronial inquiry.
- Part of the reforms of the coroner's role also required government agencies to formally respond to any recommendations made by the coroner.
- These changes led to a considerable cultural change within the coroners court itself in terms of
  engagement with and curiosity about service system issues and broader cultural changes
  among those involved in coronial inquiries particularly police and counsel assisting.
- Suicide was selected as one of the priority areas for the prevention unit. The primary purpose of the register is to inform coronial practice and the availability of it to more broadly inform practice and look at system issues is a secondary benefit.
- Deaths are added at time of referral where flagged as potentially being a death by suicide. Rich
  array of information is coded, as well as descriptive entries. Information is then updated/added
  to as the inquiry progresses.
- Funding for the register is a key issue with the initial government funding and subsequent beyondblue funding now having expired. The primary cost of the register is the time involved in coding the material obtained through the coronial inquiry into the system. This is a labour intensive process and there is a learning curve for the individuals entering the data. Also need to consider rotation of personnel or mix of responsibilities as can be traumatic for those coding.
- Data linkage is a possibility although has been minimal to date. However, making the data
  accessible to others to analyse (such as to explore epidemiological or system questions) has
  been encouraged and has progressed subject to usual government processes.
- Note that for data linkage/broader research generally need at least 5 years of data to have robust enough data set. This means having secure funding to maintain the register over an extended period of time rather than year to year grants or short term research grants.
- The University of Melbourne is currently completing its evaluation which is likely to be published later this year or in early 2017.

## Queensland model

- Queensland's register is managed by the Australian Institute for Suicide Research and Prevention (AISRP) with funding from the Mental Health Commission. AISRP currently maintains two versions of the QSR – a Final QSR database (QSR) of finalised cases from 1990 on and a preliminary database - Interim QSR (iQSR) with weekly updates since 2011.
- Collects a broader set of deaths, both those deemed suicide by coroner and those where the
  coroner did not make that finding but that there is some probability that it may have been a
  suicide (with that judgement made according to a research classification system. This
  recognises that coroners' findings as to suicide are fine judgements that can be somewhat
  subjective. Accordingly, there will often be benefit in looking at cases that fell on the non-



- suicide side of a somewhat indistinct line. Near misses may provide as good learning opportunities as direct hits.
- As with the Victorian Register, codes a wide range of data including demographic variables, circumstances of death, variables pertaining to physical and mental health, and significant life events before the death – employment, medical treatment etc.
- Feedback received suggests that access to the Queensland data by other researchers has been problematic.

## Western Australia

- While Western Australia does not have a suicide register, the Western Australian Mental Health Commission has an extensive program of work with regard to suicide data. This includes:
  - system of notification from coroner's office of all newly referred matters
  - establishment of a comprehensive data set through coding of all coronial records of suicides from 1986 on in partnership with Telethon kids
  - partnership with Education specifically looking at rapid responses to suicides by school students.
- Potential future directions to expand on the existing work includes:
  - inclusion of suspected deaths by suicide for inclusion in the data set developed in partnership with Telethon kids
  - data linkage with Health records (including emergency departments and police)
  - consideration of self-harm data.