

Evaluation of the National Suicide and Self-harm Monitoring Project and System | Final report

Executive summary



THE UNIVERSITY OF
MELBOURNE

Background and context

Suicide and suicide prevention

Suicide is a major public health problem in Australia and worldwide. Each year, more than 3,000 Australians take their own lives. For every death by suicide, there are approximately ten times as many hospitalisations for intentional self-harm in Australia. Previous self-harm is one of the strongest predictors of future suicide.

To assist with suicide prevention efforts, there is a need for greater attention to early indicators and interventions to reduce distress, self-harm, and suicide in the community. The World Health Organisation has identified the importance of the monitoring and surveillance of suicide and self-harm as a core component of national suicide prevention strategies. Monitoring rates and risk factors for suicide and self-harm is critical for timely, targeted, and effective intervention and postvention support services.

The National Suicide and Self-harm Monitoring Project and System

The National Suicide and Self-harm Monitoring Project (the Project) was announced as part of the Prioritising Mental Health Package in the 2019–20 Australian Government Budget. The Australian Institute of Health and Welfare (AIHW) is leading the Project in collaboration with the Department of Health and the National Mental Health Commission (with staff members from each organisation together forming the Project team). Advice on the development and implementation of the System is being provided by an Expert Advisory Group that comprises lived experience representatives, state and territory government representatives, researchers, and suicide prevention experts.

The National Suicide and Self-harm Monitoring System (the System) brings together existing and new data on suicide and self-harm in Australia. The System includes a Public Facing Monitoring Site (the Published Site) which is designed for public users and the State and Territory Information Portal (the Portal) which is designed for authorised users. The Project includes the activities required to build the System and data development to improve the collection, supply and timeliness of suicide and self-harm data reporting. There are also additional project activities contributing to improving the performance and utilisation of the System including the use of the System for monitoring population mental health impacts during COVID-19 via the National Cabinet and Prime Minister's reporting (the Dashboard).

The overall aim of the System is to assist the Australian Government and state and territory governments to achieve the objectives of the Fifth National Mental Health and Suicide Prevention Plan, including the commitment to improving the quality, accessibility and timeliness of suicide and self-harm data. Improved national surveillance and data will support policy makers, service providers, communities and researchers to identify trends, emerging areas of concern and priority groups in the population. Improved surveillance and data will assist these stakeholder groups to better respond to suicide and self-harm through appropriate policy making and suicide prevention and postvention activities, and in time, lead to a reduction in suicide and self-harm in the community.

Evaluation approach

Our team, from the University of Melbourne, undertook an evaluation of the Project and System between May 2020 and December 2021. The purpose of the evaluation was to assess elements of the development of the System, as well as the initial performance and effectiveness of the System. Evaluation findings aimed to inform future quality improvements over time including considerations as to where to prioritise future development efforts and aspects related to the maintenance of the System.

The objectives of the System are to function as a public health surveillance system by integrating suicide and self-harm data and research to monitor trends in these health-related events, disseminate this information and provide feedback loops to those involved in planning and responding to suicide prevention and support public community awareness and understanding of suicide and self-harm. The project objectives include: the development of an integrated monitoring system in collaboration with key stakeholder groups and; data development to improve data collection and supply pertaining to suicide and self-harm and enhance the timeliness and comprehensiveness of data.

The evaluation drew on the Centre for Disease Control and Prevention (CDC) Guidelines for Evaluating Public Health Surveillance Systems to answer the overarching question: To what extent is the System meeting its aim and objectives? The CDC framework also guided the assessment of the following key system attributes: data quality, sensitivity, simplicity, timeliness, accessibility, acceptability, and usefulness.

The evaluation gathered information from six data sources: (a) a review of key documents; (b) observational and participatory data; (c) a data audit of the Published Site; (d) semi-structured interviews with stakeholders involved in the development and/or use of the System, and with international experts with experience of other systems from around the world; (e) two case studies focused on two organisation's use and perceived usefulness of the System (Case Study 1: Western NSW Primary Health Network's use of the Published Site and Case Study 2: Australian Department of Health's use of the System for the Dashboard and; (f) routinely collected website analytics data from the Published Site. Information from these data sources were triangulated to answer the evaluation question.

Summary of findings

System development and related project activities

Key Impacts

The Published Site went live in September 2020. It is now the most comprehensive public resource of Australian data and information on both suicide and self-harm. The Published Site has resulted from significant work by the Project team related to data management and reporting, as well as ongoing development of content and maintenance of the site. A prototype of the Portal has been developed and undergone initial beta testing. However, advice from the Expert Advisory Group in mid-2021 suggested that prior to external user testing and roll-out of the Portal, further stakeholder consultation should be conducted. This included consultation with other potential user audiences and the development of a working group dedicated to drafting guidelines for the Portal to occur in parallel with its early development. The Portal will continue to be developed in 2022.

Collaboration with data custodians, government departments, people with lived experience, and the broader sector has been a notable feature of the development of the System and is now embedded as a key activity. Meetings and workshops have enabled end-user perspectives to shape iterative design and development of the System, and have supported general stakeholder buy-in, awareness and understanding of the System. The importance of the lived experience perspective to guide the development of the System has been especially prominent, reflecting the genuine commitment of the AIHW and project partners to ensure that key decisions about the System were informed by the voices of people who have been affected by suicide.

The Project has involved additional streams of activity. Through these activities, there has been major progress in terms of public reporting of more timely data sources for suicide and self-harm (through the Published Site), including using these sources to support public awareness and understanding of the impacts of COVID-19 on population mental health and suicide. New processes and products (e.g., the Dashboard) have been produced that have supported intra- and inter- government data sharing, and subsequent data-driven policy and planning. Additionally, the AIHW and the National Mental Health Commission have commenced the development of a continuous quality improvement framework to guide improvements and sustainability of the System over time.

Challenges

The multi-component nature of the Project and the System, and the commitment to further development will require significant ongoing technical input, management of roles and responsibilities of project partners, ongoing relationship-building with data custodians, and broad sector consultation and input. An ongoing challenge will be determining how to focus Project efforts and allocate resources across the multiple components, especially as the System enters a maintenance phase. It will also be important to consider how the continuous quality improvement framework encapsulates monitoring of the System's ongoing performance and how this information then feeds into strategic planning for further development.

System performance: data quality and sensitivity

Key impacts

Data quality refers to the completeness and validity of the data recorded in the System and the sensitivity of the System to detect deaths by suicide and instances of self-harm. The data audit of the Published Site, conducted in January 2021, indicated that there was excellent internal consistency between visualisations of the data and their associated supplementary data tables on the site, and strong agreement with source data sets published elsewhere. The AIHW has applied current best practice methods to ensuring high-quality data is presented on the Published Site and have a rigorous process for internal data quality review.

The data audit in combination with ongoing interaction with the Published Site over the course of the evaluation period, revealed tangible evidence of continuing efforts to publish data on instances of suicide and self-harm for different geographic regions (including at the Primary Health Network (PHN) level) and specific population groups (such as young people, Australian Defence Force personnel and Aboriginal and Torres Strait Islander people) to increase the representativeness of the data. There has also been additional content added to the Published Site on behaviours and risk factors associated with suicide.

Challenges

In the data audit, some small differences were found between what was reported on the Published Site and the source data and other data sets. Such inconsistencies are expected in Australia due to differences in definitions and data collection methods and coding practices between data custodians and jurisdictions. These and other inconsistencies in data reporting are issues that the Project seeks to improve through data development activities. Representation of population sub-groups (particularly those that are over-represented in suicide and self-harm statistics) is especially important for prevention efforts. However, it is often difficult to report data for these sub-groups because small numbers mean that cells must be suppressed to ensure confidentiality. There are also issues with respect to a lack of availability and accuracy of data identifying these sub-groups within suicide and self-harm related datasets, as well as population datasets (e.g., Census data). The AIHW has commenced work to add additional sources of information for specific population sub-groups such as LGBTIQ+ people.

System performance: simplicity

Key impacts

Simplicity refers to the structure and ease of operation of the System. Based on interviews with those involved in the design and development and users of the Published Site, there was consensus that the site is user-friendly for both those who want access to high-level summary data and those who want access to more complex data. Early users of the site reported that it was easy to navigate and that the single location for multiple sources of suicide and self-harm data and access to new data sources simplified their own data collection practices. Analytics data on user engagement for the Published Site homepage showed that the most-used link was the 'Data' link, which also suggests users are finding it easy to navigate their way to the data. There was also evidence from the review of key documents and the data audit that, since the initial release of the Published site, there has been a simplification of AIHW processes for the publication of data (especially for updates to existing data).

Challenges

Based on the data audit and associated review of key documents, it is evident that the data procurement, collation, analyses, review, approval, and publication is a process that requires many steps and the involvement of many stakeholders. Interviews with custodians of other international suicide or self-harm monitoring systems confirmed that systems of this nature are inherently complex, so this is not an unexpected finding. Although these same interview participants suggested that systems can increase the simplicity of processes by integrating digital data systems for ease of flow of data between levels of reporting (or in the case of the National Suicide and Self-harm System; the flow of data from data custodians to the AIHW), such integration was seen to take time and specific investment to be achieved. Some interview participants noted they were seeking more communication and/or an index of the data housed on the Published Site to help with finding the data they were looking for but also for there to be some form of identification of the data not available on the site (e.g., data on suicide or self-harm in the LGBTIQ+ population).

System performance: timeliness

Key impacts

Timeliness refers to the speed between steps in the System and the availability of information for public use. A notable impact on the timeliness of the System has been the AIHW's achievement of collating and publishing data from jurisdictional suicide registers. Data from these registers offer the most-timely source of suicide data in Australia, and the AIHW continues to work with the custodians of these registers to increase the availability and inclusion of these data. The AIHW has also been working with state coroners and Department of Health officials in states and territories without established suicide registers, providing advice and support to assist in the establishment of registers. Also relevant to timeliness is the speed with which the AIHW has updated information on the Published Site. In 2021, the AIHW has streamlined its processes so that updates of existing time-series data such as deaths by suicide over time on the Published Site has been published within two weeks of updated source datasets being released by data custodians.

Challenges

Timely reporting of some suicide and self-harm data is difficult due to lengthy processes involved in the original collection and processing of data (e.g., thorough coronial investigations). The Project has overcome many of the traditional delays by working with timelier data sources such as suicide registries and ambulance data, as well as by making in-house process improvements to expedite publication of some data.

System performance: accessibility

Key impacts

Accessibility refers to the availability and ease of use of data and information within the System to support the understanding of suicide and self-harm and its prevention. Interview participants noted that the Published Site was well structured and therefore more accessible than some other government websites which require greater technical knowledge. There was consensus from various end-users that the collation of data in one place with the addition of visualisations and new analyses has increased the overall accessibility of suicide and self-harm data in Australia. Having prior knowledge of, or direct involvement with, the Project and System directly influenced the early access to the System, suggesting that awareness of the System has helped drive access to the Published Site. Interview participants from international suicide or self-harm systems also noted the importance of actively increasing the awareness of the System and disseminating findings to relevant stakeholders involved in suicide and self-harm prevention.

Challenges

Based on stakeholder interviews and Case Study 1, issues raised about the overall accessibility of the System included: that more awareness of the data and the System is needed in order to further its accessibility; and that the information and data presented on the Published Site should be presented in a way that is accessible to people with a range of levels of data knowledge and capability. Participants linked accessibility with data being interpretable, suggesting that simple summaries of the data for knowledge translation would enhance the accessibility of the data. Participants also discussed the need to continue conversations with a range of end user groups of the System (e.g., young people) to inform the ongoing design of the System to ensure accessibility for these groups. PHN users indicated a need for access to more granular data than what is currently provided on the Published Site, in order to better support their service planning and suicide prevention efforts. Some interview participants from international suicide and self-harm systems noted that their systems built in processes to assess potential users if they wanted access to restricted data to ensure they have the technical understanding and skill to manipulate and interpret the data. This vetting of access based on data capability may be relevant for administration of access to the Portal.

System performance: acceptability

Key impacts

The acceptability of the System refers to the willingness of persons and organisations to use it. Confirming what was noted during stakeholder consultation meetings during the development of the Published Site, interview participants reinforced that the site was responsive to the sensitivities around certain types of information presented (e.g., data on suicide methods) and the safety of the website overall. The Published Site was seen to have provided more warnings and 'self-care' messages than other government websites that contain information about suicide and self-harm, and that it maintained a good balance between informing users about the sensitive nature of the data and making the data available for use. There was also recognition that NGOs and PHNs would likely use the Published Site to ensure their work in suicide and self-harm prevention was based on the latest available data.

Data custodians from Australia who participated in the interviews indicated their relationships with the AIHW were positive, describing the AIHW team members as being engaged, having a good understanding of the data and presenting it appropriately. Custodians of international suicide and self-harm systems noted the importance of maintaining communication and working relationships with those collecting or providing access to the data.

Challenges

Based on information from interviews and the findings from Case Study 1, acceptability of the System appeared to be closely tied to accessibility of data to support local service planning and suicide prevention efforts. PHN stakeholders noted that in order to tailor their efforts for specific geographic areas and population groups, they would likely need access to more granular data than what is currently presented on the Published site. Interviewees representing LGBTIQ+ populations also raised concerns about the lack of data on the Published Site to help inform their suicide and self-harm prevention efforts. Data custodians raised a number of challenges including: a need to balance contributing data to the System with competing requests to contribute data to other initiatives, all of which are resource intensive; that they were not always sure what their data was being used for in the System; and efforts required to ensure that their data remained confidential and nonidentifiable when published in the System.

System performance: usefulness

Key impacts

Usefulness refers to the ability of the System to contribute to the prevention and management of suicide and self-harm, including by improving stakeholders' understanding of the public health implications of suicide and self-harm. Based on stakeholder interviews, the case studies and the website analytics, it is evident that the Published Site is already proving to be a very useful resource from multiple user perspectives and for various user types. From the PHN perspective, the Published Site was seen to be useful for broad knowledge and high-level suicide prevention planning, both by providing local and national contextual information and for verifying information from other sources of relevant local but potentially less reliable data. Stakeholder interviews also revealed that media professionals have been engaging with the Published Site to access suicide rates over time to write evidence-based articles, and to underpin their advocacy efforts designed to encourage government responses in suicide and self-harm prevention. Interviewees also noted that making comprehensive data available to the public means there is potential for the AIHW to control the narrative by contributing valid and reliable data to debates.

Website analytics provided strong evidence that the Published Site is well frequented and is becoming a key public resource for suicide and self-harm information in Australia. Visits to the site have increased in number, and the site has become more prominent within the broader 'parent' AIHW site. The Published Site is now the most popular destination for Google searches on 'suicide statistics in Australia' and peak periods of search activity have coincided with periods of COVID-19 extended lockdowns.

Representatives from government departments agreed that the System will be able to contribute to evidence-based policy decisions in relation to suicide and self-harm prevention. The development and use of the Dashboard demonstrated that the System and data housed within it could be leveraged for timely monitoring of COVID-19 impacts on population mental health and suicide. The Dashboard was seen to be useful at senior levels of government and was consulted when decisions were made about lockdowns and their potential impact on mental health. The Dashboard has prompted new ways of working, including facilitating data sharing between the Australian Government and some state and territory governments, and prompting regular meetings for knowledge mobilisation. There were also real-time policy outcomes attributed in part to the use of the Dashboard during 2020 and 2021, including increased provision of child and adolescent mental health clinicians in headspace clinics and additional funding for crisis lines.

Challenges

As the System is dependent on the timeliness of source data and data sharing and reporting arrangements with data custodians, improving detection of suicide and self-harm will require changes in practice, new technologies or additional analytical work. This may aid the identification of unexpected increases in suicide or self-harm and enable localised service responses. There is a potential risk that public use of the Published Site may lead to misuse or misinterpretation of data.

Recommendations

Based on the main evaluation findings, eleven recommendations are provided for consideration by the AIHW and project partners for future development, improved performance, and maintenance of the System.

It is recommended that the AIHW:

1. Identify and prioritise project activities

- 1.1. Incorporate a priority setting exercise (during strategic planning for the System in 2022) to determine what activities are 'critical' versus 'important' versus 'desirable' to deliver within the constraints of the Project team's own operational capacity, availability of resources and timelines.
- 1.2. Identify areas for improvement as highlighted in this evaluation and the continuous quality improvement framework (see Recommendation 11) and consider the best ways to leverage core capabilities and capacity of project partners for leadership and implementation of specific activities for the System.

2. Embed stakeholder consultation in the System, including people with lived experience

- 2.1. Continue to embed broad stakeholder consultation in the ongoing development and maintenance of the System. This will improve the awareness, accessibility, acceptability and usefulness of the System over time. The voice and contribution of people with lived experience of suicide should continue to be prioritised as part of the System.

3. Improve the collection and inclusion of data in the System for certain groups in the population with specific reference to Part 9 Section 111 of the National Mental Health and Suicide Prevention Agreement

- 3.1. Continue to look for opportunities to conduct and collaborate on projects to improve data collections and reporting for sub-groups that are over-represented in suicide and self-harm statistics (for example, children and young people (including those in out-of-home care), Indigenous people, ex-serving Australian Defence Force personnel, LGBTIQ+ people, people with chronic disease and/or disability, injured workers, people with mental illness, people with alcohol and drug use disorders, people experiencing homelessness, older Australians, people experiencing socio-economic disadvantage, and people who have experienced contact with the criminal justice system). These data are critical for informing policy and targeted suicide prevention efforts which make them a good fit for inclusion in the Portal but also, where possible, for inclusion on the Published Site to support public awareness and understanding. We acknowledge this may take time as these data that would identify people as belonging to some of these groups aren't currently captured in suicide and self-harm collections or in population level statistics.

4. Improve the timeliness and coverage of data in the System

- 4.1. Focus on current sources such as the suicide registers and the National Ambulance Surveillance System data as well as exploring new technologies and additional analytical work with these data, to improve closer-to-real-time detection of unexpected increases of suicide and self-harm, and to ultimately inform prompt and localised service responses.
- 4.2. Lead further exploratory data development work over the short term, in order to improve ongoing real-time monitoring of suicide and self-harm (including the potential inclusion of alert systems) and new models of service responses. This will require the collaboration and support of data custodians, state and territory governments and sector leaders including the National Mental Health Commission. It will also require a longer time horizon (i.e., more than 2 years) to achieve.

5. Explore other data sources for inclusion in the System

- 5.1. Explore the availability and suitability of service use data such as visits to general practitioners and police attendances while also continuing to support quality improvement of emergency department presentation data for self-harm.
- 5.2. Collaborate with local and state level jurisdictions in Australia that may already have some rudimentary systems in place for collection of these data. There may also be lessons from some international systems (e.g., the National Police Agency Suicide Data System in Japan, the CDC Emergency Department Surveillance of Nonfatal Suicide-Related Outcomes in the USA, and the CDC National Violent Death Reporting System in the USA).

6. Explore further data linkage opportunities with specific reference to Part 7 Sections 92-95 of the National Mental Health and Suicide Prevention Agreement

- 6.1. Explore opportunities for further data linkage projects to support national data linkage and sharing of linked data, for use in policy, planning system management, evaluation, and performance reporting. These projects may improve understanding of risk factors for suicide and self-harm and in doing so, support intervention programs that are targeted towards those who are at heightened risk of suicide and self-harm.

7. Improve the accessibility, acceptability, and usefulness of the Published Site

- 7.1. Continue to work with the National Mental Health Commission to build awareness of the site through ongoing direct communication and marketing efforts and regular consultation with various end-user stakeholders, and by leveraging established sector networks and leadership to also spread the word.
- 7.2. Consider providing a 'sign up for updates' service on the Published Site to broaden communication of updates and alert interested users of these updates as they go live.
- 7.3. Consider building a website feedback tool or pop-up survey to gather ongoing user insights and feedback that can inform development and marketing efforts.
- 7.4. Include simple data summaries and infographics to make it easier for public users, including media professionals, to interpret more complex information housed on the site.
- 7.5. Include an index of all data that are available to aid quick searching for specific data. A statement of what is not available on the site due to data gaps could also quickly orientate users of these gaps and/or to works in progress.
- 7.6. Publish more data and research on suicide and self-harm among particular sub-groups (e.g., Indigenous Australians, CALD communities, LGBTIQ+ people) to improve the visibility and accessibility of information for these sub-groups and the organisations that represent them.

8. Improve the accessibility, acceptability and usefulness of the System for PHN users

- 8.1. Provide PHN users with a level of tailored access to the Portal that includes access to more granular suicide and self-harm data by geographic region and population sub-groups, to inform targeted and localised suicide and self-harm prevention and management work.
- 8.2. Provide PHN users with more information on individual and community risk factors for suicide and self-harm as well as access to more timely data and data from other community services such as police data and general practitioner services.
- 8.3. Support PHN users to access academic and published research and evaluation articles and reports in suicide prevention as part of the System.

9. Improve the process and production of the Dashboard

- 9.1. Develop an interactive, on-line platform for the Dashboard (or incorporate it into the Portal) to improve its usefulness for government and for furthering consultation between participating state jurisdictions, the AIHW and the Australian Department of Health as to additional data sets that could be shared in the Dashboard for reciprocal benefit to policy and service planning.
- 9.2. Leverage the approach that was utilised for the Dashboard for more timely and ongoing reporting within the Portal component of the System for different user audiences such as PHNs.

10. Improve the acceptability of the System for data custodians

- 10.1. Consider providing further written guidance to data custodians so that they have a clear understanding of their requirements for contributing data to the System and how their data will be used and reported in the System.
- 10.2. Continue to work with data custodians to routinise processes of providing data and analyses to the System which over time should streamline data transfer.
- 10.3. Facilitate the establishment of a national network of data custodians of suicide and self-harm data to support the development of nationally consistent approaches to governance, data sharing and data access.

11. Support quality improvement for the System

- 11.1. Update the program logic that was initially developed to focus measurement priorities and guide this evaluation. The program logic should be updated with input from management and governance groups for the System and include input from lived experience representatives. This will ensure that there is a shared understanding and agreement of the processes, impacts and outcomes to be achieved by the System as well as making explicit the underlying assumptions that the program logic is based on.
- 11.2. Include system performance indicators that measure specific aspects of the implementation and performance of the System over time while providing early warning of potential system deviations. These ideally should be aligned to attributes (i.e., data quality and sensitivity, simplicity, accessibility, acceptability, timeliness, and usefulness) deemed of greatest importance for System performance. System indicators are not seen to be static but can evolve over time as the System too evolves.
- 11.3. Integrate information flowing from the continuous quality improvement framework into strategy cycles for the System and project management processes to support decision making, accountability, learning and innovation.

Strengths and limitations of the evaluation

While embedding evaluation as a core part of the development and establishment of the System has enabled an early assessment of the System's development and performance, the System is likely to continue to evolve and the resulting performance, as well as the utilisation of the System by various end-user audiences, will also change over time. There is value in conducting further evaluation at a later point in time when the System has matured, especially in relation to end-user utilisation and the associated usefulness of the System.

Conclusion

The National Suicide and Self-harm Monitoring Project and System are important Australian Government initiatives designed to improve the quality, accessibility and timeliness of data on suicide and self-harm in Australia. This evaluation has demonstrated that the Project and System are well on track to achieving their objectives, particularly in relation to the collaborative, ongoing development of the System and the creation of a 'one stop' comprehensive, high-quality resource for the public for suicide and self-harm data in Australia. There was also strong tangible evidence of genuine progress in relation to improving data collection and supply, including enhancing the timeliness and comprehensiveness of suicide and self-harm data. The System has been well accepted by those individuals and organisations with a stake in the System, and the broader public. The System is being utilised and has been shown to be useful from various user perspectives and for various uses. As the System continues to develop and the Portal is established, further evaluation may be helpful for understanding the System's ongoing performance and its ability to contribute to evidence based suicide prevention policy and practice.