



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

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Use of terms and key acronyms

Term / acronym	Definitions / name
Suicide and Self-harm Monitoring System	The National Suicide and Self-harm Monitoring System brings together existing and new data on suicide and self-harm.
The System	The Suicide and Self-harm Monitoring System.
Suicide and Self-harm Monitoring Project	The Suicide and Self-harm Monitoring Project includes the activities required to build the System as well as data development activities to improve the collection, supply and timeliness of suicide and self-harm data reporting. The project is comprised of two phases. Phase 1 is the development of the Public Facing Monitoring Site. Phase 2 is the development of the State and Territory Information Portal.
The Project	The Suicide and Self-harm Monitoring Project.
The Project team	Staff of the Australian Institute of Health and Welfare, National Mental Health Commission and Department of Health working on the Project. In this report 'the Project team' refers to the group as a whole while

sometimes the text refers to work done or recommendations for specific member organisations of the Project team (for example, the AIHW).

The Public Facing Monitoring Site	Brings together existing and new morbidity and mortality data related to suicide and self-harm from across Australia into a public website that provides interactive data visualisations, geospatial mapping and information on current suicide prevention activities and services.
The Published Site	The Public Facing Monitoring Site.
The State and Territory Information Portal	Brings together existing and new morbidity and mortality data related to suicide and self-harm from across Australia into a secure environment. It is designed to contain additional information than the Public Facing Monitoring Site. Authorised users will have access to these data in the State and Territory Information Portal to aid policy evaluation, service planning and activities. While the name for this component of the System is yet to be finalised, this report will refer to the full name of this component as the State and Territory Information Portal.
The Portal	The State and Territory Information Portal
Phase 1	Development of the Public Facing Monitoring Site.
Phase 2	Development of the State and Territory Information Portal.
CDC	Centre for Disease Control and Prevention
AIHW	The Australian Institute of Health and Welfare
EAG	The Expert Advisory Group Subcommittee of the National Suicide and Self-harm Monitoring System
PHN	Primary Health Network
NGO	Non-Government Organisation
LGBTIQ+	Lesbian, Gay, Bisexual, Transgender, Intersex, Queer and Questioning communities.
CALD	Culturally and Linguistically Diverse Communities.
The Dashboard	The mental health reporting dashboard for reporting to the National Cabinet and Prime Minister's Office.

Executive summary

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 Office 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 National Cabinet and Prime Minister's Office reporting (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 have 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 users, 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 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.

1. Purpose and structure of this report

In early 2020, the University of Melbourne was commissioned by the Australian Institute of Health and Welfare (AIHW) to undertake an evaluation of the National Suicide and Self-harm Monitoring Project and System. The National Suicide and Self-harm Monitoring System (the System) brings together existing and new data on suicide and self-harm in Australia and includes a Public Facing Monitoring Site (the Published Site) designed for public users, and the State and Territory Information Portal (the Portal) designed for authorised users. The Suicide and Self-harm Monitoring Project (the Project) includes the activities required to build the System as well as data development activities to improve the collection, supply and timeliness of suicide and self-harm data reporting. The evaluation was conducted between May 2020 and December 2021 and was focused on evaluating the Project and the associated development, initial performance and effectiveness of the System.

This is the final evaluation report which reports on all research activity conducted throughout the evaluation, the key findings and recommendations for future quality improvement and maintenance of the System. Sections 1 and 2 provide background information about the Project and System, and Section 3 outlines the design, approach and data sources used in the evaluation. Sections 4–8 provides the detailed methods and results related to each of the data sources. Section 9 provides a synthesis of key findings related to the evaluation questions, recommendations for future quality improvement and the ongoing maintenance of the System, strengths and limitations of the evaluation and, the final conclusion for the evaluation.

2. Setting the context

2.1. Suicide, self-harm and suicide prevention

Suicide is a major public health problem in Australia and worldwide. Every year, more than 3,000 Australians take their own lives (1). This equates to more than eight deaths by suicide each day. Concerningly, the rate of suicide in Australia is trending upwards: from 10.7 per 100,000 people in 2008 to 12.1 per 100,000 people in 2020 (1). For every death by suicide there are approximately ten times as many hospitalisations for intentional self-harm in Australia (2, 3) which is one of the strongest predictors of future suicide (4, 5).

Suicide is a complex human behaviour that usually results from multiple factors interacting with each other over time rather than from a single cause (6). Recognised risk factors for suicide extend beyond mental ill-health and include social stressors such as unemployment, relationship breakdown, financial distress and social isolation (7). While many people who experience one or more of these factors do not experience suicidality, the accumulation of numerous factors have been shown to increase distress and risk of suicidal behaviour (7). Although suicide is pervasive across the Australian population, affecting people from all types of backgrounds and throughout the lifespan, some groups are disproportionately impacted by suicide. For example, suicide is the leading cause of death for younger Australians aged 15–44 and Aboriginal and Torres Strait Islander people (hereafter, respectfully referred to as Indigenous people) have rates of suicide that are almost double those of non-Indigenous Australians (1). Every life lost to suicide is a tragedy, and the ripple effects for family, friends, colleagues and communities are profound, far reaching and often long lasting. It has been estimated that up to 135 people are impacted by each suicide death (8).

To assist with suicide prevention efforts, there is a need to shift greater attention to early indicators and supports to reduce distress and self-harm behaviours in the community. This shift requires improved monitoring across the spectrum of suicidal behaviour and a better understanding of population and community level risk and protective factors for suicide. These data can then be utilised to improve timely responses and supports to those in need, underpin targeted suicide prevention policy and activity, support research and evaluation, and increase community awareness and understanding of suicide and self-harm.

2.2. Monitoring of suicide and self-harm in Australia

Public health surveillance systems are critical for informing public health practice. They are essential for quantifying and illustrating public health issues, identifying risks and protective factors, and evaluating interventions for prevention and treatment (9). 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 (10). However, there has been a paucity of high quality and timely data to inform preventive efforts in most countries around the world. This is particularly the case for self-harm surveillance data derived from hospitals and other community services. Monitoring rates and risk factors for suicide and self-harm is critical for timely, targeted and effective intervention and postvention support services.

In Australia, although the national monitoring of suicide and self-harm has occurred in some form for many decades, until recently, there have been notable data gaps and limitations related to aspects of quality, timeliness, breadth and accessibility of these data. For example, there is a reliance on key data sources for suicide deaths from the Australian Bureau of Statistics (ABS) Cause of Death data, which is reported annually, and which depends on coroner reported suicide deaths from the National Coronial Information System. The National Coronial Information System includes all deaths due to injury and unnatural causes in Australia. A death by suicide is only counted by the National Coronial Information System once the coronial inquest is

complete which takes a median of 19 months (11). Difficulties determining suicidal intent and variation in coronial processes at the state and territory level may also influence coding and therefore identification of cases. This means that by the time of reporting, national data reflects a previous state and not the current reality of suicide within the community. This is especially problematic when external factors such as natural disasters like bushfires or pandemics occur and there is a need to monitor real-time impacts of these on population suicide numbers and trends. Some jurisdictions, acknowledging the lengthy time delays for case identification of suicide deaths, have developed suicide registers to code 'probable suicides' within 24–48 hours and prior to coroner case closure. These registers typically rely on police reports or death certificates as their primary source of evidence for the preliminary classification (12) and have demonstrated a good degree of correspondence with completed coronial inquest information (13). This has increased provision of timely reporting to government departments within the same jurisdiction to inform suicide prevention efforts, though access to, and reporting of, these data to the broader suicide prevention sector, until very recently, has been limited.

There have also been issues with the availability of accurate, timely and comprehensive data on the incidence of self-harm in the community. At the national level, there has been a reliance on a single source of data; hospital admissions data counted in the National Hospital Morbidity Database to present a national picture of morbidity related to self-harm. However, these data are collated and released annually with a 12-month lag. They also do not allow for disaggregation of cases for intentional self-harm with suicidal intent and intentional self-harm without suicidal intent. Additionally, many acts of intentional self-harm, whether with suicide intent or not, neither lead to death or hospitalisation but may result in interaction with other health and community services such as emergency department presentations, ambulance attendances, presentations to general practitioners, calls to crisis lines and police attendances. While emergency department presentations for self-harm are being collected in some form Australia wide (14), there are known issues with the quality, completeness, and comparability of these data between jurisdictions, suggesting that data development is required to improve this source of national data. Furthermore, collection of timely data from multiple services, across the spectrum of self-harm behaviours, has been identified as key to providing a more comprehensive picture of the state of self-harm in the community and opportunities for closer-to-real-time suicide prevention responses. One such data source to emerge is ambulance data. What was initially developed in 2012 as part of a research project by Turning Point, Eastern Health, and Monash University in Victoria has led to consistent coding of ambulance clinical records for presentations for suicidal ideation, suicide attempt, and self-injury across most Australian states and territories. This has provided an additional data source (now named the National Ambulance Surveillance System covering 90% of the Australian population (15)).

2.3. Policy developments for improving monitoring of suicide and self-harm in Australia

In 2017, the Australian Government released the Fifth National Mental Health and Suicide Prevention Plan 2017–22 (16). This plan outlined a whole of government, whole of community approach to suicide prevention requiring co-ordinated, cross-portfolio and multisectoral action to address a raft of socio-cultural, economic, health, occupational and environmental factors for suicide prevention. It also outlined the need for improved monitoring of suicide and self-harm as a key priority. In 2019, Prime Minister Scott Morrison pledged commitment to working towards zero suicides through a range of policy initiatives and programs, including the appointment of the first National Suicide Prevention Adviser. Most recently, the House of Representatives established a Select Committee (December 2020) to inquire into mental health and suicide

prevention, including reviewing recent strategic reviews of the current mental health system and impacts of the 2019 bushfires and COVID-19 Pandemic, as well as the capacity of the mental health workforce.

With this increasing national policy focus on mental health and suicide, a number of landmark reviews have been conducted and subsequently, documents were released over 2020–21 including the Productivity Commission Inquiry into Mental Health Final Report (17) and the Interim and Final Advice reports from the National Suicide Prevention Adviser (18). These documents signal in-principle recommendations for system and sector reform related to mental health and suicide prevention including specific recommendations focused on; the need to improve access to accurate and timely data, addressing data gaps, and improving data usability critical to supporting evidence-based policy and practice. The House of Representatives Select Committee presented its final report in November 2021.

Furthermore, Suicide Prevention Australia, the peak body representing the suicide prevention sector in Australia has identified data gaps as a key concern of the sector and a key pillar for their own policy and advocacy work. Based on survey results (published in September 2021) from the 'State of the Nation in Suicide Prevention Survey', which gathered insights from member organisations and the broader suicide prevention sector, 79% of survey participants agreed that there were gaps in data collection systems for suicide prevention and 72% said they would benefit from access to real-time data on ambulance visits and emergency department presentations (19).

2.4. Overview of the National Suicide and Self-harm Monitoring Project and System

The National Suicide and Self-harm Monitoring 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) was originally funded by the Australian Department of Health at \$5 million per year for 3 years (from 2019–20 to 2021–22) to manage the Project which is responsible for developing and implementing the National Suicide and Self-harm Monitoring System. Further funding of A\$4.2 million per year for the System (until 2025) was announced in the 2021–22 Australian Government Budget, reflecting a commitment to continuing the System beyond the initial project end date of June 2022. The 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). An Expert Advisory Group (EAG) that comprises lived experience representatives, state and territory government representatives, researchers, and other professionals from the suicide prevention sector is providing advice as required for the development and implementation of the System. The Project is also drawing on expertise from subject matter experts as needed, as well as the National Injury Surveillance Unit at Flinders University (a collaborating unit of the AIHW).

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 (16). These include the commitment to improving the quality, accessibility and timeliness of suicide and self-harm data. Improved national surveillance and data will support mental health and suicide prevention 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.

The Project has two main objectives:

- To build an integrated monitoring system which will collate and report data on suicide and self-harm, and support the accessibility and usefulness of data;
- To undertake data development activities to address identified data gaps, improve data collection and supply pertaining to suicide, suicide attempts and self-harm, and enhance the timeliness and comprehensiveness of data.

These two objectives are being addressed concurrently during the Project. The first is being addressed through the development of the System over two phases. Phase 1 is the development of the Public Facing Monitoring Site (the Published Site) which presents national morbidity and mortality data sources and is intended for public users. The Published Site has been available to the public since September 2020 and is continuing to be updated with new data and information. Phase 2 is the design and development of the State and Territory Information Portal (the Portal) which is intended to hold more granular data for specialist users with authorised access. The prototype platform for the Portal was developed in early-mid 2021 and further development and access to the Portal by specific user audiences will become available over time (late 2021–22). Figure 1 provides an illustration of the Project’s timeline. For further detail of the System architecture, see Section 2.5.

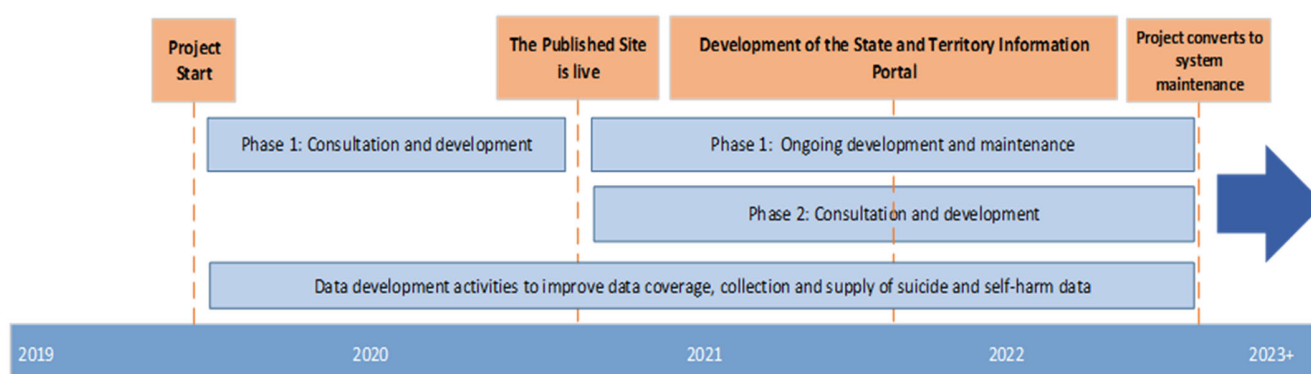


Figure 1: Timeline of the National Suicide and Self-harm Monitoring Project.

The second objective is being addressed through a variety of ongoing data development activities. These activities are designed to ensure that data collected, collated and reported in the System are high quality. The activities will also improve system efficiencies, and the overall timeliness and comprehensiveness of data through incorporation of additional data sets. For example, over time, data sets from additional services may be included such as emergency department presentations, presentations to general practitioners, and police attendances to provide a broader, more in-depth understanding of suicide and self-harm in the community. Furthermore, increasing the utilisation of existing data sources through data linkage projects and bespoke research to answer high priority policy questions (especially around social risk factors), will also be conducted and made accessible either on the Published Site or the Portal. There are also numerous other related activities being conducted as part of the Project and System to maximise the utility of the System for public health policy and action. Figure 2 provides an overview of all streams of activities associated with the project.

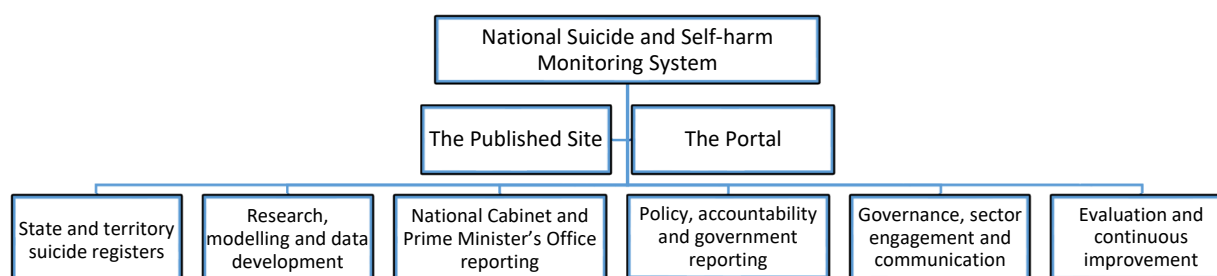


Figure 2: AIHW project streams of activity contributing to the National Suicide and Self-harm Monitoring System.

The Project was initially due to be completed by 30 June 2022 however, with further funding secured for the System, the AIHW will continue to maintain the Project and continue to develop and support quality improvement of the System over time. It is likely to take time to settle into a steady state of implementation and for the System to be maximally utilised.

2.5. The System architecture

This brief overview of the structure of the monitoring system reflects the state of the System as of November 2021. As the Project continues into 2022, it is likely that some elements of the System will alter over time.

The System has been designed to integrate existing and new suicide and self-harm data from across Australia (see Section 5.2 for information on key data sources), as well as suicide and self-harm reports and research into a single system. Below is a very brief description of the two main components of the System; the Published Site and the Portal, and then a description of the System working as a public health surveillance system.

2.5.1. The Published Site

The Published Site has been available to the public since September 2020 via the AIHW website. The Published Site has been designed to increase community awareness and understanding of suicide and self-harm, including by dispelling myths and misconceptions and providing regional and demographic insights to assist community planning and responses. The Published Site is an interactive data site that:

- collates existing and new morbidity and mortality data and reports of suicide and self-harm;
- configures this information to provide time-series data;
- provides contextual information relevant to each data source (including data limitations and information on coding and classification of cases);
- provides regional and demographic insights where available;
- links to international data where relevant;
- links to descriptions of source data;

- provides contact information for support services (e.g., Lifeline, Beyond Blue, Suicide Call Back Service);
- presents information with consideration of *Mindframe* guidelines;
- provides links to other relevant AIHW data collections, Australian and international research papers and reports; and
- data visualisations using Tableau© technology, including geospatial mapping for some data sets.

Visualisation and reporting of data have been made available with the following considerations:

- privacy and confidentiality of the data;
- regional reporting and its limitations;
- statistical confidence in reporting emerging trends and cohorts; and
- the timeliness of data (due to known limitations of specific data sources and/or time to upload the data to the monitoring system).

For a comprehensive review of data sources and datasets presented on the Published Site see Section 5.2, as well as the data downloads page of the Published Site (<https://www.aihw.gov.au/suicide-self-harm-monitoring/data/data-downloads>). The Published Site has continued to undergo regular scheduled data updates as more recent published data has emerged and new content and data sources have been added to the site.

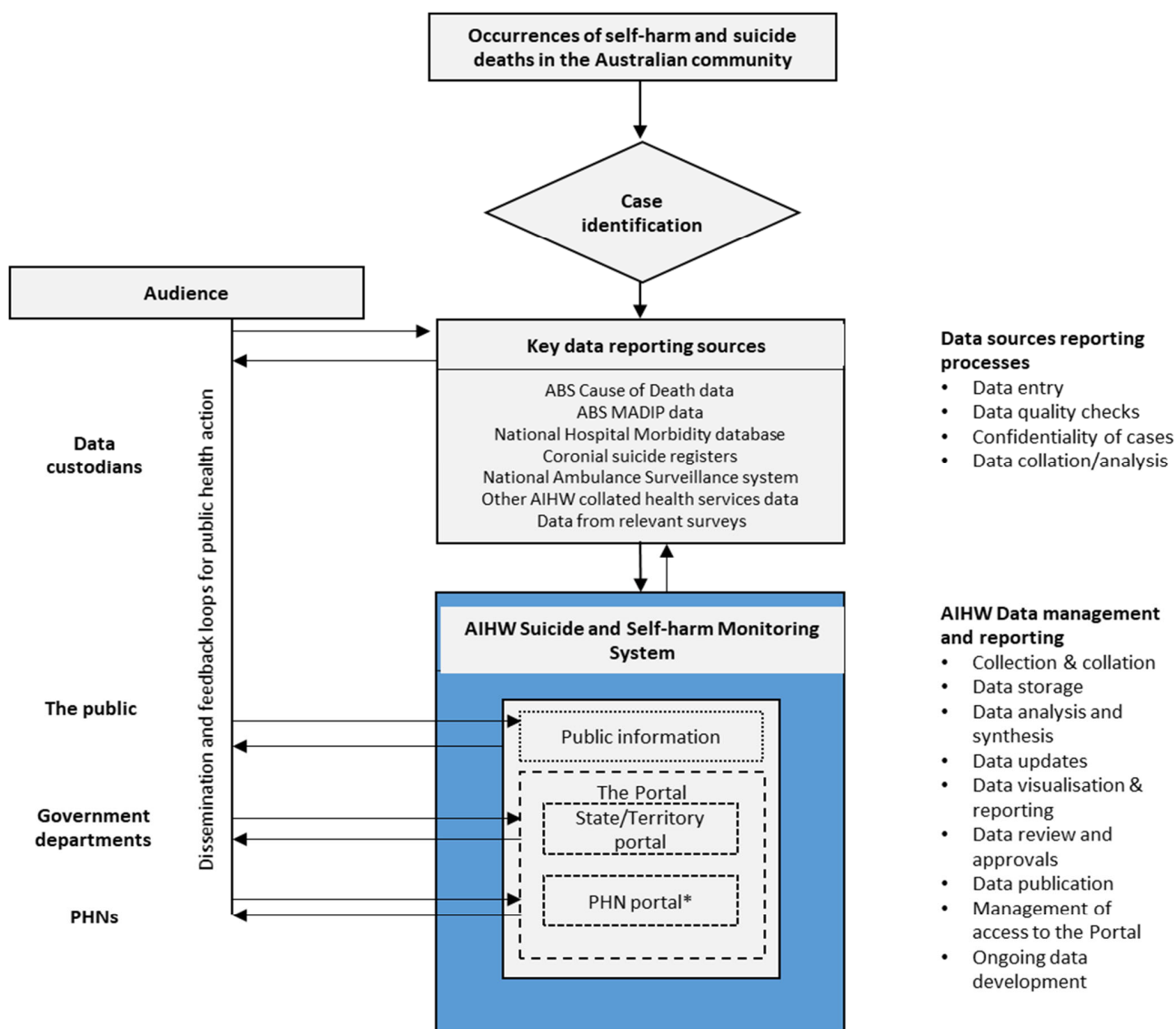
2.5.2. The Portal

The Portal is a secure portal with specific content that is not available to the general public and is to be accessible by data custodians and other authorised users. The Portal is hosted within the Published Site and is designed to have a more fine-tuned surveillance capacity and provide more in depth understanding of trends and characteristics of suicide and self-harm (e.g., within regions and demographic groups). The Portal may also include, in the future, additional data on psychosocial risk factors associated with suicidal behaviours and deaths. Data earmarked for the Portal are not to be released publicly for a range of reasons, including that they may be considered more sensitive in nature and raise privacy considerations, may be prone to misinterpretation, or may not be consistent with the *Mindframe* guidelines for the responsible reporting of suicide (20) (e.g., an in-depth focus on suicide methods). Data that have not yet been peer-reviewed for public release may be included in the Portal to provide authorised users with more immediate access while the approval process for publication to the Published Site is undertaken. These data may also be more complex in nature and require that users have additional data analytical capabilities to appropriately analyse and interpret them. The Portal will initially include aggregated national morbidity, mortality and ambulance attendance data with the potential to be further disaggregated than what is possible on the Published Site. However, no unit level data will be provided on the Portal and data will only be disaggregated in a manner that maintains confidentiality and allows for statistically robust interpretations to be made. States and territories may choose to contribute other data to the System (e.g., suicide register data, police data, other hospital and health services data) but the AIHW will control the inclusion of all data on the site.

The Portal, while initially conceived as being for state and territory government users, may also be extended to other users such as Primary Health Networks (PHNs), researchers and others who are involved in planning and providing responses in suicide prevention. This will require the creation of additional access points that have tailored information for the specific user audience.

2.5.3. The System

The System overall is seen 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. It is also disseminating this information and providing feedback loops to those involved in planning and providing responses for suicide prevention. It also supports public community awareness and understanding of suicide and self-harm. See Figure 3 for an illustration of the System, represented as a type of public health surveillance system.



PHN = Primary Health Networks, The Portal = State and Territory Information Portal, *PHN portal = information in the Portal tailored to PHN level of access. The Portal may be expanded to include other sector stakeholders and researchers.

Figure 3: A representation of the National Suicide and Self-harm Monitoring System as a type of public health surveillance system.

3. Evaluation of the Project and System

3.1. Scope and purpose

The regular evaluation of public health surveillance systems is considered an important aspect of development and maintenance of these systems to ensure they are achieving their objectives and are providing valuable and useful information for stakeholders (10). In choosing to embed evaluation from the outset, the AIHW commissioned the University of Melbourne to undertake an independent evaluation of the Project and System.

The evaluation ran alongside the initial development and early implementation of the System from May 2020 to December 2021, gathering and analysing information over this time. The purpose of the evaluation was to assess elements of the design and development of the System, as well as its initial performance and effectiveness. We designed the evaluation 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. We previously developed a detailed evaluation plan (21) in close consultation with the AIHW. As the development of Project and System were iterative, we modified the evaluation over time to ensure that its activities were appropriate, that it was aligned to the Project timelines and that it remained fit for purpose.

3.2. Evaluation framework

The evaluation drew on the Centre for Disease Control and Prevention (CDC) Guidelines for Evaluating Public Health Surveillance Systems, an evaluation framework that is used to support an assessment of surveillance system performance and efficiency (22). The CDC guidelines consider public health surveillance systems to include systems that are used to: measure the burden of disease and monitor trends in health-related events (such as suicide and self-harm); guide immediate action in relation to these events; guide the planning, implementation and evaluation of programs designed to prevent these events; evaluate public policy; detect changes in practice and examine the effects of these changes; prioritise the allocation of resources, and; provide a basis for clinical and epidemiological research (22). Using this definition, the Suicide and Self-harm Monitoring System is regarded as a public health surveillance system (see Section 2.5.3).

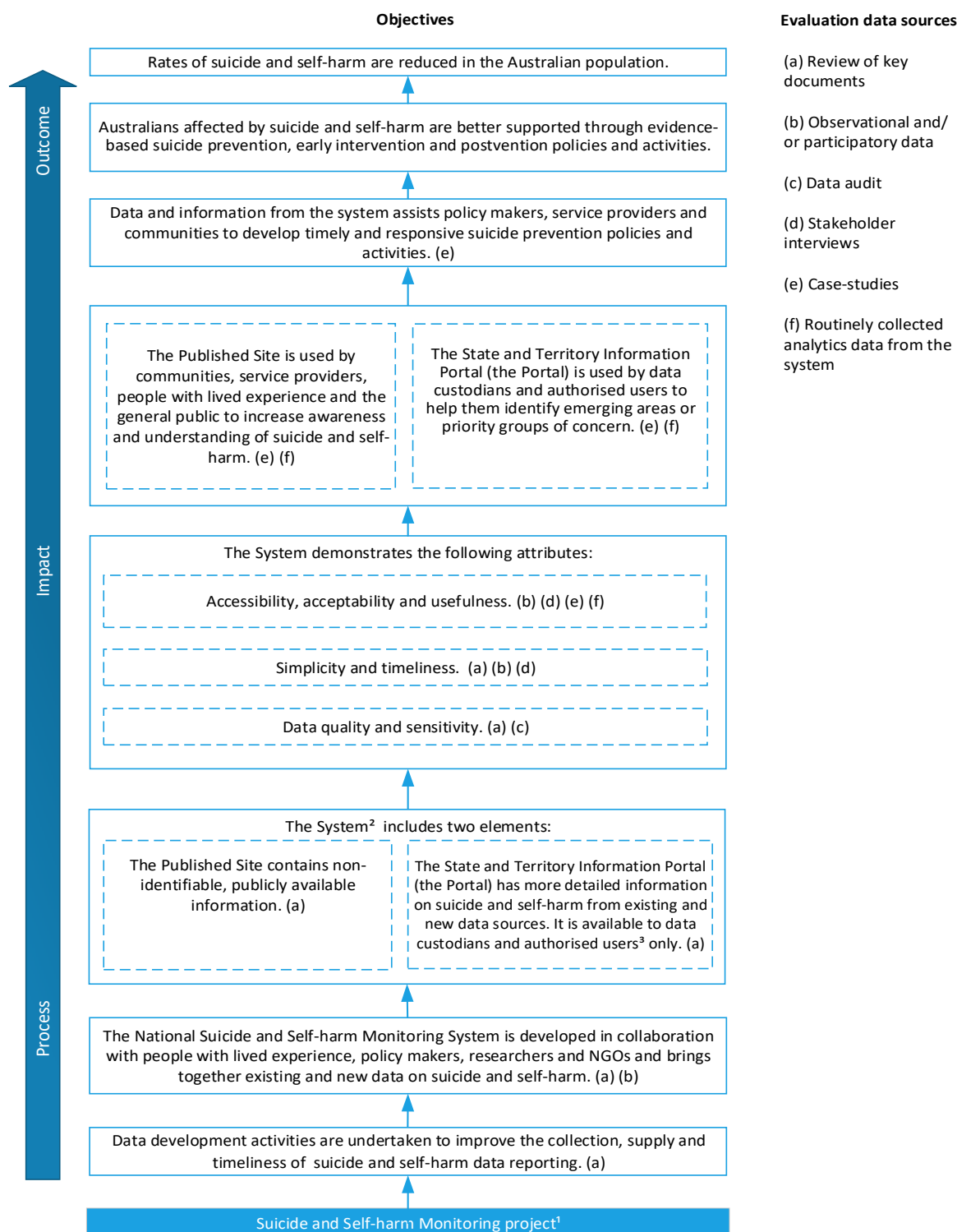
The CDC framework sets out overarching questions that evaluations of public health surveillance systems seek to answer, including the question: To what extent is the system meeting its aims and objectives? This evaluation was focused on this key evaluation question. The CDC framework also includes specific guidance for the assessment of important system attributes of a well performing public health surveillance system but suggests focusing on those attributes that are most relevant to the objectives and type of surveillance system being evaluated. The evaluation of the System assessed the following attributes: data quality, sensitivity, simplicity, timeliness, accessibility, acceptability, and usefulness. Table 1 provides a brief definition of these terms as applied to the evaluation.

Table 1: Centre for Disease Control and Prevention attributes as applied to the National Suicide and Self-harm Monitoring System.

Attribute	Definition
Data quality	The completeness and validity of the data recorded in the System.
Sensitivity	The ability of the System to detect true suicide and self-harm instances and/or rates.
Simplicity	The structure and ease of operation of the System for users.
Timeliness	The speed between steps in the System such as the consideration of the time between the initial case capture and the availability of information for use for public health planning and intervention.
Accessibility	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.
Acceptability	The willingness of persons and organisations to participate and/or use the System.
Usefulness	The ability of the System to contribute to the prevention and management of suicide and self-harm including an improvement in stakeholders' understanding of the public health implications of suicide and self-harm.

3.3. Program logic

We developed a program logic for the Project and System (see Figure 4) which is represented as a series of objectives that form a hierarchy and align with the processes and the intended impacts and outcomes of the Project and System. The logic assumes that the higher order objectives are contingent on achievement of lower order objectives. Together, these objectives highlight the shared understanding among project partners and key stakeholders as to what the Project and System is intended to do and what may change as a result, although it is not a definitive model. The program logic also provided a focal point for evaluation planning and supported mapping of evaluation methods and associated data sources to objectives. The information from the data sources helped to verify the extent to which objectives were achieved at different levels of the hierarchy. As the evaluation was conducted during the development and early implementation of the System and prior to it being in a sustained and steady state of operation, evaluation of process and impact level objectives were the focus of the evaluation.



¹ Suicide and Self-harm Monitoring project is the name given to the project being led by the AIHW to develop the National Suicide and Self-harm Monitoring System.

² 'The System' is a synonym for the National Suicide and Self-harm Monitoring System.

³ 'Authorised users' are users that have been approved by data custodians to access data in the State and Territory Information portal.

Figure 4: Objectives hierarchy forming the program logic and associated evaluation data sources.

3.4. Evaluation data sources and approach

The evaluation gathered information from six data sources:

- review of key documents;
- observational and participatory data;
- data audit;
- semi-structured interviews;
- case studies; and
- routinely collected analytics data.

The primary data sources were the data audit, semi-structured interviews and case studies. The document review, observational and participatory data, and routinely collected analytics data were supplementary data sources. Triangulation of these primary and supplementary data sources was conducted to support overall synthesis and understanding of information to answer the evaluation question (see Section 3.5 on analysis and synthesis). Each of these data sources enabled an assessment of the extent to which given objectives in the program logic had been achieved (see Figure 4) as they relate to the System development (i.e., what was developed and how), and System performance and effectiveness (i.e., assessment of stated attributes and including the use and usefulness of the System for public health interventions).

The methods we used to collect and analyse data for each source are described in Sections 5–8 dedicated to reporting on each data source. Data collection from each source was captured over time to correspond with the development and roll out of Phase 1 (development of the Published Site) and Phase 2 (development of the Portal) of the System as well as the ongoing data development and other project activities. It is important to acknowledge that the Project and development of the System are continuing beyond the evaluation timeframe and whilst the Published Site has been established and is operational, the Portal component of the System is still being developed. For this reason, the evaluation did not assess the performance and use of the Portal component through an assessment of the stated CDC attributes, though it did include commentary on aspects of its development (up to November 2021). Throughout the evaluation, we also monitored external factors such as the influence and impact of the COVID-19 pandemic and the associated lockdowns, on the Project and the System.

3.5. Data analysis and synthesis

We analysed each data source individually (see individual data source Sections 5–8 for information on the approach to analysis for each data source) then triangulated them to support overall synthesis and understanding of information to answer the evaluation question. Triangulation facilitates validation of data through cross verification from two or more sources and tests the consistency of findings obtained through different methods.

3.6. Reporting of results

Evaluation reporting was planned to occur mid-way (March 2021) and at completion of the evaluation (December 2021) in the form of interim and final reports. The timing of these reports was determined to enable evaluation findings to inform ongoing development and quality improvements.

The interim report provided a summary of evaluation activity from May 2020 to February 2021 and some preliminary findings related to the Project activities and development of the Published Site. The interim

report has been published on the Published site at: <https://www.aihw.gov.au/suicide-self-harm-monitoring/research-information/releases>.

This final report provides an overview of all evaluation activity conducted for the entire period of the evaluation (from May 2020 to December 2021) and reports findings for each data source (see Sections 5–8). The results from each data source have then been triangulated and summarised in the discussion section (see Section 9) to determine the achievement of objectives noted in the program logic (see Section 3.3). The main impacts and challenges associated with achievement of objectives is reported with the assessment of each of the CDC attributes presented individually for ease of reporting, though these attributes are not mutually exclusive; for example, the accessibility and timeliness of the System will impact the usefulness of the System. Furthermore, the findings from the assessment of the Published Site and broader project activities, are likely to be useful for informing aspects of ongoing Portal development, therefore findings have been framed with this intention in mind.

3.7. Ethics approval

This evaluation was conducted in accordance with the National Health and Medical Research Council Guidelines on Ethical Conduct in Human Research and the Australian Research Council Australian Code for the Responsible Conduct of Research. The University of Melbourne Human Research Ethics Committee approved the evaluation in September 2020. As we designed this evaluation to be iterative, amendments to the original ethics application were applied for and approved at various timepoints throughout the evaluation, as further information about the methods of the evaluation were established.

3.8. COVID-19 context and research conduct

Due to COVID-19 restrictions in Australia and specifically in Victoria, we conducted all data collection and analysis was remotely. Consideration for the impact of COVID-19 on the Project, System and the evaluation have also been addressed as part of the overall synthesis of findings and recommendations made in this report.

4. Review of key documents and observational and participatory data

4.1. Our approach

4.1.1. Review of key documents

We reviewed more than 60 documents provided and approved by the AIHW, National Mental Health Commission and the Australian Department of Health that were relevant to the evaluation and that specifically addressed and demonstrated evidence of:

- activities and processes conducted as part of the Project to develop and implement the System as well as evidence of data development activities; and
- insights into specific attributes and performance of the System, including data quality, sensitivity, simplicity, timeliness, accessibility and acceptability.

These documents included work plans, system guidelines and processes (including data quality statements and business rules), meeting minutes and presentations, project progress reports and various other written communication documents targeted at a variety of audiences including; internal governmental audiences, project advisory groups, external mental health and suicide prevention sector audiences. Documents were provided to our team at initiation of the evaluation but also on an ad-hoc basis as the Project and System progressed and the documents became available. We assessed documents for suitability for review, compiled the relevant documents, then developed a data collection template in excel to guide data extraction and summarise information as they related to specific program objectives noted in the program logic. See Appendix 1 table 11 for further details of the types of documents reviewed as part of the evaluation.

4.1.2. Observational and participatory data

We attended 24 meetings and workshops during the evaluation period (e.g., User Experience Working Group meetings, Meeting of the EAG, media and suicide prevention sector briefing webinars, the Portal PHN Consultation Workshops, the Portal Working Group, the Lived Experience Advisory Working Groups). These meetings and workshops were attended by a broad range of stakeholder groups (e.g., people with lived experience of suicide and self-harm, government officials, PHN representatives, NGO representatives, researchers etc.). We also attended fortnightly update meetings throughout the evaluation period with the AIHW with representatives from the National Mental Health Commission and the Australian Department of Health present on occasion. Through these meetings, we received verbal and written updates of project activities, including data development activities as they progressed over the course of the Project. See Appendix 1 tables 9 and 10 for further details of the meetings attended as part of the evaluation.

This data collection method was both participatory and observational because we observed some meetings and actively participated in others. The aim of this attendance was to enable a deeper understanding of project activities and processes contributing to the development of the System, including stakeholder involvement as well as insights into System attributes (i.e., acceptability, accessibility and usefulness of the site) and performance over time from various stakeholder perspectives. To capture participant and user experiences, we took notes on key points related to project activities and stakeholder feedback to support evaluation of related objectives noted in the program logic (see Figure 4). Written observational and participatory data from meetings and workshops were combined and reviewed with data from associated

documentation (e.g., agendas, minutes, and papers), using the same methods as described in the document review previously.

4.2. Key findings

The information from these meetings and documents have been summarised into three areas that align with objectives in the program logic: stakeholder involvement in the design and development of the System; insights into attributes of the Published Site during development and; data development and related activities as part of the Project.

4.2.1. Stakeholder involvement in the design and development of the System

From the initiation of the Project, the AIHW, together with the National Mental Health Commission and the Australian Department of Health, have intentionally engaged with a broad range of organisations and individuals with a stake in the System. The Project partners have leveraged their sector relationships and collaborative networks with data custodians, government departments, people with a lived experience of suicide, and the broader sector to conduct either point-in-time consultation or ongoing advisory and working groups for the System. The meetings and workshops have helped to incorporate end-user perspectives to shape iterative design and development of the System but have also supported general stakeholder buy-in, awareness and understanding of the System. The EAG have met on a quarterly basis each year since late 2019 and continue to provide advisory input for all aspects of project management and further directions for the development of the System. Overall stakeholder meetings were well attended (higher than 80% attendance), and participants appeared highly engaged and comfortable to voice their opinions and respectfully and collaboratively work through issues with the Project team.

A notable finding was the prominence and importance of the lived experience perspective in guiding the Project and development of the System. People who had experienced suicidal ideation or made a suicide attempt, supported others through a suicidal crisis, and/or been bereaved by suicide were present at all the meetings and workshops attended by the evaluation. In these meetings, they actively contributed to decision-making for the Project and System alongside other sector and government stakeholders. Lived experience participants also presented the personal perspective of suicide at media and sector webinar briefings when the Published Site was launched in September 2020 and then again for a major update of the site in October 2021. They also presented on the System alongside the AIHW and National Mental Health Commission at the 31st World Congress of the International Association for Suicide Prevention in September 2021. Furthermore, the National Mental Health Commission ran lived experience user workshops with specific population groups (e.g., young people) to gauge their views of the Published Site.

Lived experience participants also met as part of a dedicated Lived Experience Advisory Working Group for the System led by the National Mental Health Commission. These meetings provided the opportunity for further discussion of aspects of the System and the role and contribution of lived experience to the Project and System overall. At the November 2021 meeting of the Lived Experience Advisory Working Group, participants were invited to share their reflections on being involved with the Project and System. Participants acknowledged the significant breadth and depth of lived experience consultation for the Project and the value placed on it. They commended this as a positive achievement and noted it modelled new ways of working in the suicide prevention sector. For example, one participant mentioned the power of providing the lived experience perspective alongside the release of annual deaths by suicide statistics. They noted that

this emphasised the human impacts represented in every statistic and commented that this was something they had not seen done before. The group also noted where there was room for improvement including; increasing the diversity of lived experience representation in the group and therefore informing the project; supporting capability building of lived experience participants in their knowledge of suicide and self-harm data and statistics; supporting data custodians to work with people with lived experience; and further highlighting and celebrating the lived experience participation within the broader suicide prevention sector.

4.2.1.1. The Published Site

The development of the Published Site commenced in late 2019 and it was launched at the end of September 2020. Since the Published site went live, it has undergone a series of updates: updates of data already presented on the site (non-embargoed updates) and; updates that contained new types of data or significant changes to how data was presented (embargoed updates). These updates have coincided with scheduled releases of data as well as new sources of information and analyses, or new visualisations of the data, presented on the site for the first time (see Section 5.3. for more information on these updates over time). Prior to the initial launch and before each major update of the Published site over 2020 and 2021, the User Experience Working Group attended workshops to provide timely advice and feedback on key elements of the design and content to be published. Early prototypes of visualisations were presented and live examples of navigation around the site were used to prompt discussions with stakeholders. Stakeholders were invited to provide feedback in their preferred way. During the workshops, the Project team responded to questions about the design and development of the Published Site. Members of the AIHW provided further rationale and context for design and content choices, explaining key terms, data challenges and limitations, and what was in scope for further iterations. This Q&A style interaction enabled in-depth discussion about key components of the Published Site and made the limitations and challenges transparent to stakeholders. Over time, the membership of this working group broadened, with the inclusion of additional lived experience representation and suicide prevention research and data experts. It is understood that the User Experience Working Group will be an ongoing source of stakeholder input and as such, has become embedded within the AIHW Approval and Reviews processes for major updates to the Published Site (see Section 5.3 for more information on this process) signalling that the AIHW are dedicated to this collaborative way of working with the sector and end-users.

4.2.1.2. The Portal

The AIHW commenced formal development of the Portal in early 2021, engaging website developers to create a minimal viable product with two factor authentications for access. Beta testing of the Portal commenced with internal AIHW staff in June 2021. Further user testing of the access and initial content by external user audiences is scheduled for December 2021 into early 2022. The Portal was originally envisaged by the AIHW as a secure portal for exclusive use by state and territory government departments to access aggregate and anonymised data not available on the Published Site due to the data being considered sensitive or prone to misinterpretation. Additionally, states and territories would be able to contribute other data to the System to complement the existing data for their own jurisdictional use, although the AIHW would control the inclusion of all data in the Portal.

In order to design the Portal with end user needs in mind, the AIHW and National Mental Health Commission conducted a user design workshop with stakeholders from the Australian Capital Territory in March 2021. Participants were from relevant organisations involved in suicide prevention and service planning. The workshop aimed to introduce the Portal concept, gain insights into what type of data would be useful in the

Portal, and how they would use the Portal for their service planning and suicide prevention activities. Participants were interested in the Portal providing data on risk factors for suicide, wanted geocoded data at a finer level, and were interested in tools and Excel documents that would enable them to analyse the data themselves. Further Portal workshops with stakeholders from other states and territories are planned (from 2022 onwards).

At the EAG June 2021 meeting, participants signalled interest in a tailored portion of the Portal also being accessible to PHNs and potentially other user groups (e.g., researchers and NGO service providers of crisis call lines) in the future. Some key challenges were also identified for the development of the Portal including its novel nature and lack of precedents to learn and model from. Participants noted the need to be transparent with the sector as to who is able (and not able) to access the Portal, and what data are housed in it, in order to avoid misconceptions. The EAG agreed to the development of guidelines (in parallel to early development of the Portal) to govern what data are housed in the Portal compared with the Published Site as well as the administration, access and use of the Portal when implemented.

Two further streams of consultation designed to inform the Portal development commenced in July 2021, namely PHN consultation workshops and the Portal Working Group. For the former, the AIHW and the National Mental Health Commission partnered with the Black Dog Institute and SAS Institute® to convene four user design workshops with nationwide representation from ten PHNs, one Australian Defence Force Community Health Group and one Aboriginal Community Controlled Health Organisation. The consultations aimed to determine the data needs and preferences of these PHNs and other commissioning organisations. Feedback and information from these workshops were collated and synthesized and reported back to the AIHW to inform future development. Some of the key findings noted in the final presentation and report (23) included that:

- Most PHNs and other commissioning organisations were utilising a wide range of currently available data sources to report on suicide and self-harm for service planning and preventative strategies however, there were varying levels of data maturity and capability across PHNs. Only some PHNs reported having dedicated data science and epidemiology resources.
- The most common resources accessed by PHNs, and other commissioning organisations were data from the AIHW, Australian Bureau of Statistics, and coronial and registry data (including the National Coronial Information System), with all participating PHNs using at least one of these sources.
- PHNs and other commissioning organisations would like access to more granular data including data on suicide deaths and self-harm by demographic characteristics and geographical areas to support commissioning of tailored prevention activities and services for priority populations and within local regions.
- The collection and access to historical self-harm data was viewed as a significant problem; separate sources were known to exist (e.g., ambulance, emergency department, police data); however, these sources were not consistently available, accessible in a usable format, or not supplied in a timely manner to PHNs.
- The need to track an individual's pathway or journey over time was viewed as a key requirement for PHNs and other commissioning organisations. This pathway would identify events an individual might experience (including both self-harm and suicide attempts, as well as support received after these experiences). Currently data from the associated touchpoints (e.g., data from general practitioner consultations) where people have contact with services and supports is not readily available or accessible to PHNs and other commissioning organisations.

The report also categorised the identified PHN and other commissioning organisations needs and preferences as ‘enhancement or access to new data sources’, ‘granularity of data sources’, ‘timeliness of access’ and ‘impact and evaluation’ considerations into three horizons for future development and implementation based on the order they might be addressed. Furthermore, the report made 11 recommendations for the Portal development. The first four recommendations were broader than the immediate Portal development and related to addressing identified critical data gaps and increasing the supply of timely and reliable data from multiple community sources, particularly in relation to suicide attempt data. Recommendations five and six considered the design for the Portal in relation to how data could be presented and how PHNs might like to manipulate data. This included consideration of functions like filters to drill down in the data for different demographics groups or regions. The authors did preface that there would need to be a level of safeguard or support for users to avoid drilling down into data where small counts were observed, or where statistical invalidity and misrepresentation could potentially occur. Recommendations seven to 11 were also focused on design and content aspects of the Portal with recommendations including; incorporating an impact and evaluation tool in the Portal; adding qualitative data of lived perspectives to compliment and enrich the quantitative data; developing a catalogue of the data in the Portal for ease of navigation and communicating what is housed in the Portal; developing a community of practice for users and/or a consultancy service to support sharing of information but also to support the analysis and interpretation of data in the Portal and; development of a research repository within the Portal to house relevant research papers that could be useful to PHNs working in suicide prevention.

The Portal Working Group, led by the National Mental Health Commission, were tasked with developing the guidelines for access and use of the Portal. The Portal Working Group comprised members of the EAG, lived experience representatives, Australian and state/territory government officials, data custodians, PHN representatives, researchers and project staff from the AIHW and the National Mental Health Commission. Meetings commenced in late September 2021 and continued over October and November 2021. There were six meetings in total and the key output was the written guidelines for the Portal to be presented to the EAG and the Project team in December 2021. Five of the six meetings involved discussion about what should be included in the guidelines and fine-tuning the intent, language and tone of the specific sections within the guidelines.

Discussion at the Working Group meetings often centred around aspects of the guidelines that would govern the administration, access, content and use of the Portal. There appeared to be consensus that the information housed in the Portal ought to be localised and timely and more sensitive than the Published Site content but would still need to conform to AIHW’s privacy and ethics rules, which are governed by legislation, as well as the requirements and expectations of the data custodians. There was considerable discussion around balancing tensions between accessibility to advance understanding of how best to prevent suicide while at the same time managing risks and minimising harm due to potential misuse or misinterpretation of the data. Some Portal Working Group members suggested that the guidelines should be carefully drafted to avoid inadvertently perpetuating the stigma of suicide by implying that the public need protection from the data. The need to balance the potential risk of harm (i.e., contagion and misuse of data) with the risk of not being able to act on what is known was discussed.

When discussing potential use of the Portal, the Working Group first explored different user perspectives represented within the Working Group including Government officials; PHN and NGO perspectives and; researchers. Discussion centred around the key uses of the data for different user groups but also the types

of data and presentation of these data to maximise the utility of the Portal for each user group. There was also discussion around the role of building and enhancing data capability in the suicide prevention sector, through supporting analysis and interpretation of data for users of the Portal. Though members of the Project team pointed out that this function of the Portal may be beyond the scope of the AIHW operational capacity.

The guidelines iterated through several drafts between September and November 2021, reflecting not only the complexity of the task but also the need to incorporate cycles of detailed stakeholder feedback along the way. The Portal Working Group was also asked to consider the way in which other Australian and international systems operate when thinking about guidelines for the Portal administration, access and use. Representatives of the National Coronial Information System and the Danish Research Institute for Suicide Prevention presented to the Portal Working Group members to inform them about these other systems. Working group members noted that US systems like the National Violent Death Reporting System and the Colorado Centre for Health and Environmental Data (<https://cdphe.colorado.gov/center-for-health-and-environmental-data>) were worthy of further investigation. The final draft guidelines for the Portal included seven main sections covering: (1) Introduction; (2) Reason for the Secure Portal; (3) Purpose of the Guidelines for the Secure Portal; (4) Principles for decision making for the Secure Portal; (5). Guidelines on access to the Secure Portal; (6). Guidelines on the content of the Secure Portal and; (7) Guidelines on the use of the data in the Secure Portal. In addition to the guidelines, the Portal Working Group also developed an additional document advising on the application of the guidelines for the Portal, choosing to separate this from the actual guidelines. It is anticipated that the EAG and AIHW will review the draft documents in early December 2021, with consideration to the latter's governance structures and requirements, and the operational capacity and resources available for the development of the Portal and System overall.

4.2.2. Insights into attributes of the Published Site during development

Discussion of the accessibility and acceptability of content on the Published Site was especially prominent during the meetings and workshops. Feedback often focused on: (1) the type of language used on the Published Site, including the use of acronyms and jargon; (2) the level of prior knowledge required to understand and use the data, including understanding key statistical concepts and data limitations and; (3) whether there were sufficient contextual information and data definitions provided alongside data visualisations to support their interpretation. Stakeholders consistently acknowledged the difficulty of tailoring the Published Site to users with varying levels of experience with suicide and self-harm data. They also emphasised generic accessibility issues, such as whether the visualisations were suitable for a colour-blind audience, content had appropriate headlines, and site navigation was intuitive and easy.

Stakeholders were very complimentary about the breadth of data and associated analyses and visualisations that were available, including the focus on additional geographic and demographic breakdowns of suicide and self-harm data. There was consensus that this information was a good starting point, although stakeholders repeatedly highlighted the paucity of information about particular population sub-groups (e.g., people who identify as LGBTIQ+, injured workers, people living with chronic disease, Indigenous Australians, current or ex-serving members of the Australian Defence Force, and people living with a disability). The Project team acknowledged the importance of these priority groups and this focus was built into more recent work plans. With the presentation of more timely data on the Published Site (e.g., ambulance data being reported monthly rather than quarterly) or new research and analyses being included over time (e.g., analyses of Multi Agency Data Integration Project data), stakeholder's continued to suggest the need for further analyses and data to be included on the Published site. However, they did not always recognize the

feasibility of implementing those desired changes over the short term as reflected, on occasion, by the Project team.

In terms of acceptability, consideration of the degree of sensitivity of information presented and the safety of the website overall (particularly for vulnerable individuals who might view the site) was a prominent feature of discussion. Much of the discussion centred around how sensitive data would be presented (e.g., presentation of information about suicide methods), whether content warnings would be in place, and the prominence of signposting of help lines and support. Consideration and alignment to *Mindframe* guidelines (20) was also advised and became a regular lens through which to view major website updates. Although stakeholders viewing early prototypes and wireframes for the Published Site and additional updates noted many of these elements had been considered and included, they stressed that it would be important to continuously review and refine the site with this safety lens. Stakeholders also raised the issue of presentation of suicide data for Indigenous Australians and advised that these data should be aligned with the Closing the Gap Report (24) and *Mindframe* guidelines (20). At times, lived experience representatives provided their perspectives on how the data related to their own experiences, providing broader insights into what the data might mean at an individual level and how it might be perceived by others with a lived experience of suicide. The AIHW acknowledged these perspectives and the possibility of incorporating brief lived experience vignettes alongside data on the Published Site as part of future updates.

Stakeholders involved in User Experience Workshops were always asked to think about the usefulness of the data presented on the Published Site. Discussion of the utility of some content, including the presentation of suicide and hospitalisations for self-harm at the PHN level, led to suggestions that mapping specific user journeys might be a useful exercise to enhance understanding of the needs of specific users of the site. With website changes and data updates over time, stakeholders increasingly focused in on the additional utility that these updates afforded the Published Site as a whole, as opposed to individual content.

4.2.3. Data development and related activities as part of the Project

Data development activities designed to improve the data collection and supply of suicide and self-harm data nationally, and to enhance data sharing across jurisdictions, were also part of the broader scope of the Project alongside development of the System. Improving the data entered in the System will inevitably impact upon the attributes of the System either directly (e.g., data quality and timeliness) or indirectly (e.g., the accessibility, acceptability and usefulness of the System). The data development activities described below have been conducted over the course of the Project and evaluation period.

4.2.3.1. Publishing data from the National Ambulance Surveillance System

Turning Point was contracted to develop the National Ambulance Surveillance System for overdose and suicidal behaviour in April 2020. The National Ambulance Surveillance System is a partnership between Turning Point, Monash University, Eastern Health (Victoria) and jurisdictional ambulance services across Australia. It is a novel monitoring system that provides timely and comprehensive data on ambulance attendances for suicide attempts, suicidal ideation, self-injury, and mental health. Turning Point collate and code ambulance attendance data in all jurisdictions except South Australia and provide these data to state and territory agencies and to the AIHW for reporting on the Published Site. As of February 2021, the Published Site has provided one-month per quarter snapshots from Victoria, Tasmania, New South Wales and the Australian Capital Territory for data pertaining to 2018–20.

The frequency of reporting the National Ambulance Surveillance System data over time has increased, as have the number of jurisdictions contributing data to the Published Site. Since the first publication of ambulance data, one month per quarter snapshots for Queensland March 2020–21 have been added. As of January 2021, the AIHW has received monthly data for New South Wales, Victoria, Tasmania, the Australian Capital Territory and Queensland. Monthly data for Victoria for 2021 and comparator years 2018, 2019 and 2020 have been published on the COVID-19 page see: <https://www.aihw.gov.au/suicide-self-harm-monitoring/data/Covid-19>.

4.2.3.2. Working with state and territory suicide registers

A key goal of the broader project was to establish registers in all jurisdictions to provide timely data on suspected suicides. The COVID-19 pandemic has highlighted the need for timely data on suspected suicides to monitor impacts of the pandemic and prompt appropriate policy responses. States and territories have been supported by the AIHW to develop suicide registers and publish data from these registers. During 2020 and 2021 the AIHW:

- Obtained timely data over the course of the COVID-19 pandemic from registers in Victoria (est. 2012), Queensland (est. 2011), and Tasmania (est. 2017). These data have been informing reporting to the Prime Minister’s Office, the Department of Health and other Australian Government and state and territory government departments.
- Supported state and territory Coroners and Department of Health officials in other states and territories, with their efforts to establish suicide registers. As of November 2021:
 - New South Wales established a register in 2020 and released its first report in October 2020;
 - the Australian Capital Territory established a register in April 2021; and
 - South Australia has executed a framework to enable establishment completed in June 2021 with the aim to establish the register by the end of 2021.
- Became aware that current data were not available from the Western Australian register (est. 2010) due to changes in governance that have interrupted the coding process. In addition, legislative restrictions are currently subject to a reform process. The AIHW has continued to communicate with Western Australia to remain updated on the status of the reforms and when data collection might be reinstated.
- Have been working with the Northern Territory authorities throughout 2020 and 2021 to help establish a register.
- Received data at an agreed frequency with each of the custodians, from all established suicide registers except Western Australia. Additionally, the AIHW has approval to publish data on suspected suicides from the Victorian, Queensland and New South Wales registers. This information is found on the ‘Data from suicide registers’ page with some information also on the ‘COVID-19’ page of the Published Site. See: <https://www.aihw.gov.au/suicide-self-harm-monitoring/data/suspected-deaths-by-suicide/data-from-suicide-registers>
- Began planning to convene a meeting in 2022 with representatives of state and territory suicide registers to consider how they might work together and what can be further done with data flowing from the registers. This consultation will be conducted as part of broader conversations with regards to the development of the Portal and the flow of data from registers into the Portal.

4.2.3.3. Improving other sources of data and publishing relevant research

Work towards improving the collection of emergency department suicide and self-harm related presentation data has been undertaken. Self-harm presentations with suicidal intent are currently not identifiable in the National Non-admitted Patient Emergency Department Care Database. The AIHW is working with states and territories through the Mental Health Information Strategy Standing Committee to explore strategies for improving the quality and consistency of emergency department data, including a way of distinguishing self-harm presentations with suicidal intent from other self-harm presentations. The AIHW has written a scoping paper on opportunities and barriers to developing a consistent national data collection on suicide-related emergency department presentations. This paper includes recommendations to progress this work and has been endorsed by the Mental Health Information Strategy Standing Committee. Further discussion about next steps is likely to happen in early 2022. The AIHW continues to work with individual jurisdictions to progress emergency department data collection.

Work has been undertaken on publishing additional suicide and self-harm related data and research for specific age and population groups on the Published Site. The AIHW has identified some national suicide and self-harm studies that have been conducted with specific population groups. Throughout 2021, the AIHW have been working with the researchers who have led these studies to publish relevant data on the 'Population and age groups' page of the Published Site in future updates from late 2021 onwards. This includes data from:

- The Young Minds Matter Survey (the second Australian Child and Adolescent Survey of Mental Health and Wellbeing (25)): This was led by the University of Western Australia and funded by the Department of Health. It involved a survey of 6,000 Australian families which looked at the emotional and behavioural development of children and young people aged between four and 17 years.
- Private Lives 3 (the third of the Private Lives surveys and Australia's largest national survey of the health and wellbeing of lesbian, gay, bisexual, transgender, intersex and queer (LGBTIQ+) people (26)): This was conducted by the Australian Research Centre in Sex, Health and Society at La Trobe University. It involved a survey of 6,835 participants who identified as LGBTIQ+ living in Australia aged between 18 and 88 years.

The AIHW has funded the Australian Bureau of Statistics to continue the coding of psychosocial risk factors for all coroner-referred deaths (including deaths by suicide), guided by a manual review of police, autopsy, toxicology and coroner's reports included in the National Coronial Information System which is a source of data for the National Mortality Database. It is intended that this additional coding will be embedded in future national mortality data sets. To date the coding of 2019 risk factors has been completed and 2020 is underway. The AIHW has also worked with data from the Multi-Agency Data Integration Project to better identify risk and protective factors for suicide and has published some findings on the 'social factors and deaths by suicide' page of the Published Site. They also led an examination of service use in the last 12 months of life for people who have died by suicide using the National Integrated Health Services Information Analysis Asset in partnership with the Department of Health. The AIHW supplied a dataset to the Royal Commission into Victoria's Mental Health System that linked data from the Medical Benefits Schedule, the Pharmaceutical Benefits Scheme, the National Death Index, and specialist Victorian mental health services

records. Analysis of data from the latter dataset aimed to provide the Royal Commission with a holistic picture of the mental health system in Victoria.

Other collaborative research projects and data sharing efforts that AIHW have initiated as part of the Project include:

- Collaboration with the Australian National University's Centre for Social Research and Methods in 2020 to develop methodologies for determining incidence trends and spatial clustering of deaths by suicide and for undertaking complex modelling on deaths by suicide. Further research in 2021 extended this work to develop and validate a model and undertake analysis of spatial data from the National Mortality Database (which uses source data from the National Coronial Information System) to investigate geographical areas of persistently higher suicide rates.
- Collaboration with the Centre for Social Research and Methods on the design, and data collection of the Life in Australia™ Panel, with a focus on tracking mental health (psychological distress), substance use, social and financial outcomes during the COVID-19 pandemic. More than 10 surveys across the timespan of the COVID-19 pandemic have been conducted to date. This dataset will enable comparisons of outcomes with those of previous and future data collections throughout 2019, 2020 and 2021.
- Collaboration with the University of Melbourne's Centre for Mental Health on the effect of COVID-19 on risk factors for suicide. This project aimed to determine whether particular risk factors for suicide (e.g., financial stressors, unemployment, homelessness, and relationship difficulties) have been heightened by the COVID-19 pandemic. This project used data from the Victorian, Queensland and Tasmanian Suicide Registers. The research was conducted over 2021.

4.2.3.4. Supporting mental health COVID-19 government reporting

Since April 2020, the AIHW has supported the Department of Health Mental Health Division to use data to better understand the impacts of COVID-19 on population mental health. The AIHW has supported the collation and analysis of mental health-related activity data for National Cabinet and Prime Minister's Office reporting (the Dashboard), initially on a weekly and then on a fortnightly basis. Data reported include: Medicare Benefit Schedule mental health service use; use of Australian Government funded help lines (e.g., Lifeline, Beyond Blue and Kids Helpline); headspace service use; and information on suspected suicides from some jurisdictional suicide registers (see Table 2: Overview of data sharing between AIHW and selected jurisdictions for further details). The data were reported to the Prime Minister's Office, the Minister for Health and Aged Care, the Assistant Minister to the Prime Minister for Mental Health and Suicide Prevention, and the National Suicide Prevention Advisor. The usefulness of the Dashboard and associated processes are explored in depth in Case Study 2 in Section 7.3. Selected data were also provided to state and territory departments of health for monitoring public mental health service use during the COVID-19 pandemic. To support government monitoring of the impact of the pandemic across the whole mental health system, the AIHW have facilitated reciprocal data-sharing arrangements of national and state and territory level data with Victoria and New South Wales.

Table 2: Overview of data sharing between AIHW and selected jurisdictions.

Data sharing between AIHW and selected jurisdictions:
<p>AIHW provides to states:</p> <p>Weekly mental health related MBS service volume from 2019 to present, for Victoria, NSW, Queensland and WA, by:</p> <ul style="list-style-type: none"> • Jurisdiction; • Jurisdiction by age-group; • Jurisdiction by delivery mode; • SA3; • SA3 by age-group; • SA3 by sex and; • SA3 by delivery mode <p>Weekly answered contacts for Lifeline, Kids Helpline, and Beyond Blue, by organisation, jurisdiction and age group. (Lifeline data only includes calls. Age and jurisdiction are not known for all contacts, and there may be a high proportion of unknowns in some cases).</p> <p>States provide AIHW the following:</p> <ul style="list-style-type: none"> • Emergency department mental health presentations by SA3 and sex and age group; • Emergency department suicide and self-harm presentations by SA3 and sex and age group; • Community mental health clients and new clients by SA3 and sex and age group; • Community mental health hours and telehealth hours by SA3 and sex and age group and; • Admissions to specialised mental health units by SA3 and sex and age group

4.2.3.5. Developing a continuous quality framework for the System

At the EAG meeting in March 2021, the EAG advised the Project team to implement a continuous improvement framework that could identify and implement continuous improvement actions for the System. As a result, at the EAG meeting in October 2021, members of the National Mental Health Commission presented a draft framework for continuous improvement to the EAG. The framework was based on the “Plan, Do, Study and Act Cycle” for quality improvement (27). This Continuous Improvement Framework proposed would include:

- a model for continuous improvement to support the process and planning of continuous improvement opportunities;
- a Continuous Improvement Register to document the identification, implementation, and review of continuous improvement opportunities;
- recognition that data custodians already have quality assurance systems in place and the Framework will complement but not replicate these; and

- recognition that continuous improvement needs for suicide prevention in Australia may change over time and the Framework will work to ensure continued alignment of the System and these needs.

The proposed Continuous Improvement Framework would identify opportunities for quality improvement through: (1) consultation with the suicide prevention sector, including government representatives and people with lived experience of suicide; (2) research and evaluation; and (3) gaps analysis and service planning. The opportunities identified would be considered through the System's usual management and governance groups, including the EAG, the executive project advisory groups and the Project team. The draft Continuous Improvement Framework will be further developed in line with feedback to be received from management and governance groups in late 2021 and early 2022, and then implemented by June 2022.

5. Data audit of the Published Site

5.1. Our approach

In January 2021, we conducted an audit of the data available through the Published Site following its release to the public in September 2020. This audit aimed to evaluate the data quality and sensitivity of data available on the Published Site, both of which are attributes identified in the CDC framework and program logic. The ability of the Published Site to exhibit these attributes was evaluated by examining the internal consistency, sensitivity, completeness, and representativeness of the published data. Initial data-related processes and iterative changes of these processes over time, were also reviewed to evaluate their simplicity and timeliness.

Comparisons were made between the tables and visualisations on the Published Site, the supplementary tables that sat behind those tables and visualisations, and datasets that are publicly available through other sites and sources. The sources of the Published Site data, along with other comparable datasets were used as gold-standards for the assessment of the sensitivity of data. Comparisons checked for consistency of frequencies of deaths by suicide and instances of self-harm within the Published Site, as well as between the site and other datasets. The data audit was primarily conducted on a representative subset of visualisations and tables from the Published Site.

Data were collected from the Published Site, as well as from other public websites and reports (see Section 5.2 for a description of included data). Where possible, datasets were downloaded from the host websites and directly imported into Excel to create a data audit database. Where datasets could not be exported from their host sources data were manually entered into the data audit database. All information in the data audit database was checked against the original datasets for accuracy, and the data audit database was locked to editing. Selections of data from the database were then analysed descriptively in Excel. Counts, proportions and differences were calculated between datasets. T-tests were used to explore the significance of any identified differences.

The proportion of complete data, including the distribution of key characteristics (e.g., sex, age at death, suicide method), was assessed against both the source data and other population datasets. Representation of particular population sub-groups with higher rates of suicide and self-harm (e.g., Indigenous people, LGBTIQ+ people, injured workers, people living with chronic disease, people living with a disability, people with mental illness, people with drug and alcohol use problems, and serving and ex-serving Australian Defence Force personnel) were also examined.

5.2. Description of the data

At its launch, the Published Site contained 37 main visualisations and tables in addition to descriptive text, supplementary tables, and links to publications and other data sources. The detailed data quality and sensitivity portion of the data audit was conducted on a representative sample of 11 of the visualisations and tables, along with the corresponding supplementary tables. These specific visualisations and tables were selected because of their coverage of a range of measures including suicides, instances of self-harm hospitalisations, instances of self-harm and related ambulance attendances, and psychological distress. They presented data across a range of factors including time, gender, age, states and territories, socioeconomic areas, remoteness areas, psychosocial factors, Indigenous status, and currency of Defence Force service. The

data for these selected visualisations and tables were sourced from a range of datasets including ABS Cause of Death data, AIHW National Mortality Database, ABS National Health Survey, AIHW National Hospital Morbidity Dataset, National Ambulance Surveillance System data, and the Queensland Suicide Register.

5.3. Key findings

5.3.1. Internal consistency

Most of the visualisations and tables on the Published Site have corresponding supplementary tables. These are available for download through the 'Data downloads' page of the Published Site. More than 20% of data points were randomly selected from seven of the 11 visualisations and tables and compared to their corresponding supplementary tables to check for internal consistency and any reporting errors. All data that were checked from these visualisations and tables matched the supplementary tables. This check was not performed for the remaining four of the 11 visualisations and tables as they did not list corresponding supplementary tables.

5.3.2. Sensitivity

Online searches were conducted to identify potentially comparable datasets published as graphs, tables, or downloadable datasets on publicly available websites, or through published reports or papers. Data included on the Published Site were sourced from many of the leading organisations and Australian suicide and self-harm datasets. This meant that many of the comparable datasets available were sources of the data on the Published site. Where the identified comparable dataset was also the source for the Published Site, the audit still provided information on consistency of reporting between the published information.

One of the 11 visualisations and tables was audited because a comparable dataset could not be found. This was for ambulance presentations for self-harm and related behaviours/conditions and it was because the data were published for the first time on the Site. Comparisons were made for the remaining 10 visualisations and tables, for which comparable publicly available datasets could be found. Where a supplementary table was listed, the supplementary table was used for this comparison. Data pulled directly from the published visualisations and tables were used for the four without listed supplementary tables. In many cases, the most comparable datasets found were not directly comparable as they used different categories and aggregated the data in different ways. In these cases, comparisons were made for the data in as many different aggregated variations as were possible. Comparisons were not made with datasets that reported aggregate data where the definition for the aggregated cells did not match the definition for the data on the Published Site.

Five of the audited visualisations and tables presented exactly the same data as the comparison datasets. Four were found to have some data differences but were not significantly different. One visualisation was compared to three different comparison datasets, one of which presented the same data, and two of which presented data with differences that were not significant.

The five visualisations and tables that reported the same data as the comparison datasets presented data about psychosocial risk factors for suicide deaths, proportions of people with high and very high psychological distress, suicide deaths by Indigenous status and sex for Australia (excluding Victoria, Tasmania and the Australian Capital Territory), age-standardised suicide mortality ratios of Australian Defence Force personnel, and age-standardised monthly suspected suicide rates in Queensland. The data sources for these visualisations and tables were the ABS Cause of Death data, ABS National Health Survey data, AIHW analysis

of linked Personnel Management Key Solutions and National Death Index data, and data from the Queensland Suicide Registry. In each of these five cases, the comparison dataset was pulled from publicly available data downloads or reports from the same sources. In these cases, each data point was an exact match to the comparison dataset.

Two of the visualisations and tables that reported similar data to comparison datasets were about intentional self-harm hospitalisations in young people, and intentional self-harm hospitalisations by states and territories.

Both of the visualisations of intentional self-harm hospitalisations (one relating to young people and one by states and territories) used data sourced from the National Hospital Morbidity Database and were compared to publicly available, downloadable subsets of data from the same database, covering all but the final time period reported on the Published Site. For the visualisation focusing on young people, 29 of the 81 compared data points differed by one count of hospitalisation each. In total, the data on the Published Site reported an additional 10 intentional self-harm hospitalisations for young people over the comparable years. The difference was not found to be significant ($p > 0.99$). For the visualisation presented by states and territories, comparisons were made to two different subsets of the National Mortality Database; totals for Australia per year were compared to one subset, and hospitalisations for each state and territory were compared for a single year to another subset. The majority of data points in the first comparison differed by up to nine counts of hospitalisation. When comparing across states and territories for a single year period, only three states differed and only by one each time. Neither of the comparisons for this dataset were significantly different ($p > 0.99$).

The other two visualisations and tables that reported similar data to comparison datasets measured suicide deaths and were both sourced from the National Mortality Database and ABS Cause of Death data. The first of these looked at suicide deaths by remoteness area, and the second by socioeconomic area and mechanism. These were both compared to publicly available, downloadable subsets of the National Mortality Database. For both comparisons, data from the visualisation had to be aggregated across years for a summed five-year period. Due to the aggregation of the comparison dataset, the visualisation reporting data by remoteness area could only be compared for persons (not males and females). Data from the visualisation differed from the comparison dataset by between nine fewer and 150 more suicide deaths across the categories compared. The total difference was 292 more suicide deaths reported on the Published Site and these differences were not found to be significant given the large number of total suicide deaths reported ($p = 0.98$). Comparisons for the socioeconomic areas and mechanisms visualisation could only be made for all mechanisms by socioeconomic area, rather than by each listed mechanism by socioeconomic area. Data from this visualisation differed to the comparison dataset by between 63 fewer and 245 more suicide deaths across the compared categories. The total difference was 229 more suicide deaths, and there was no statistical evidence that these differences were significant ($p = 0.91$). Of note, the total suicide deaths reported over the same five-year period in the two visualisations differed from each other, as did the total suicide deaths reported both comparison datasets.

The final visualisation reported on suicide deaths in Australia from 1907–2019 by sex. This visualisation used data sourced from the National Mortality Database and ABS Cause of Death data and was compared with three separate datasets: a subset of ABS Cause of Death data; a subset of the National Mortality Database; and data presented in the Suicide in Australia: Trends and analysis: 1964–2018 report(2). The ABS cause of death data from 2010–19 was compared to the data reported in the visualisation and every compared data

point was an exact match. Data presented in the report table from 1994–2017 was compared to the visualisation data for persons for each year and by sex for those years summed together. The visualisation on the Published Site reported 43 fewer male and 23 additional female suicide deaths across the period compared with the report. The visualisation reported a range of 84 fewer to 75 more suicide deaths for all people across each of the included years compared with the report. Neither of the comparisons to the report data were significantly different ($p > 0.99$). The final comparison for this dataset was made to an available subset of data from the National Mortality Database for males and all persons in 2018. The visualisation data reported 72 fewer male and 92 fewer total suicide deaths compared with the datasets from the National Mortality Database. A t-test could not be conducted due to the limited data cells available.

The majority of data available on the Published Site matched comparison datasets. Inconsistencies in data reporting on suicide deaths and instances of self-harm are expected in Australia due to differences in definitions and data collection methods between data custodians, jurisdictions, and over time. For example, the data examined from the Suicide in Australia: Trends and analysis: 1964–2018 report and the National Hospital Morbidity Database included deaths coded with ICD-10 codes X60-X84 but did not include those coded with Y87.0. ABS Cause of Death data and the data presented on the Published Site reflects the updated best practice for intentional self-harm deaths of including those coded with Y87.0. Additionally, the Published Site and ABS Cause of Death data both include a time series adjustment of Victorian deaths which affected multiple years. When the audit was conducted, this adjustment had not yet been made to all datasets, including the comparison datasets used from the National Mortality Database.

5.3.3. Completeness and representativeness

The 11 audited visualisations and tables contained more than 3,000 data points combined, of which 24 (less than 1%) were not published. Each of these unpublished data points were for age-standardised rates that could not be calculated due to low numbers (e.g., Indigenous female suicides in 2003, or female suicide deaths in very remote areas per year). Seven of the visualisations and tables audited presented data by sex, four by age categories, three by state/territory, and all across a range of time periods. In order to suppress small numbers and maintain confidentiality, not all combinations of key characteristics were able to be reported on the Published Site. For example, data on suicide deaths by mechanism would likely contain many cells with small numbers and therefore have many cells unable to be published if they were presented by year, sex, age, and states and territories. Compared with other datasets used in the sensitivity analysis, information reported by the Published Site covers a large range of the key population characteristics available for these data.

The audit of this information was conducted across all data presented on the Published Site, rather than just the subset included in the more detailed data quality and sensitivity portion of the data audit. The Published Site includes sections for reporting on suicide deaths and instances of self-harm instances in young people, Indigenous people, and serving and ex-serving Australian Defence Force personnel. Each of these sub-groups had limited data reported with young and Indigenous people only having reports of suicide deaths and self-harm instances, and Australian Defence Force personnel only having suicide deaths reported. Much of this reporting was unlikely to be possible on the Published Site due to the small numbers that would result from these breakdowns. Data relating to suicide deaths of Indigenous people were not able to be reported across all Australian jurisdictions due to issues with data collection in the source datasets for some states and territories.

Very little information was reported for people with disability (“limitation of activities due to disability” was an identified risk factor presented in the visualisation of most frequently occurring psychosocial risk factors in suicide deaths). No information was reported for other population sub-groups including LGBTIQ+ people, people with chronic disease, injured workers, people with mental illness and people with drug and alcohol use problems were also examined. This information was also not reported in the other datasets used in the detailed data quality and sensitivity portion of the data audit suggesting a dearth of these data in Australia more broadly. One of the challenges to reporting on rates of suicide and self-harm for population sub-groups is a lack of numerator and denominator data about these sub-groups. Baseline numbers of people within each sub-group within Australia are necessary (e.g., Census data), as well as relevant data at the time of the death or self-harm incident (e.g., hospital admissions, coroners’ records).

5.3.4. Simplicity and timeliness related to data processes

A review of the System’s processes relating to the collection, analysis and reporting of data for the Published Site was conducted to evaluate the simplicity and timeliness of these processes. A key document provided to our team by the AIHW described more than 20 steps involved in building data visualisations for the Published Site. Figure 5 presents a summary of these steps and processes.

Sourcing the data, negotiating terms of use and contracts with data custodians, and establishing data transfer were expected to be difficult processes at the beginning of the Project. Data sourced from within the AIHW would have been faster, and required less negotiation, fewer contracts, and less complex data transfer protocols. Once in place, arrangements with data custodians will likely require few changes for new or updated data to be used in the System. New arrangements may be needed if different data are required to be added to the System in the future.

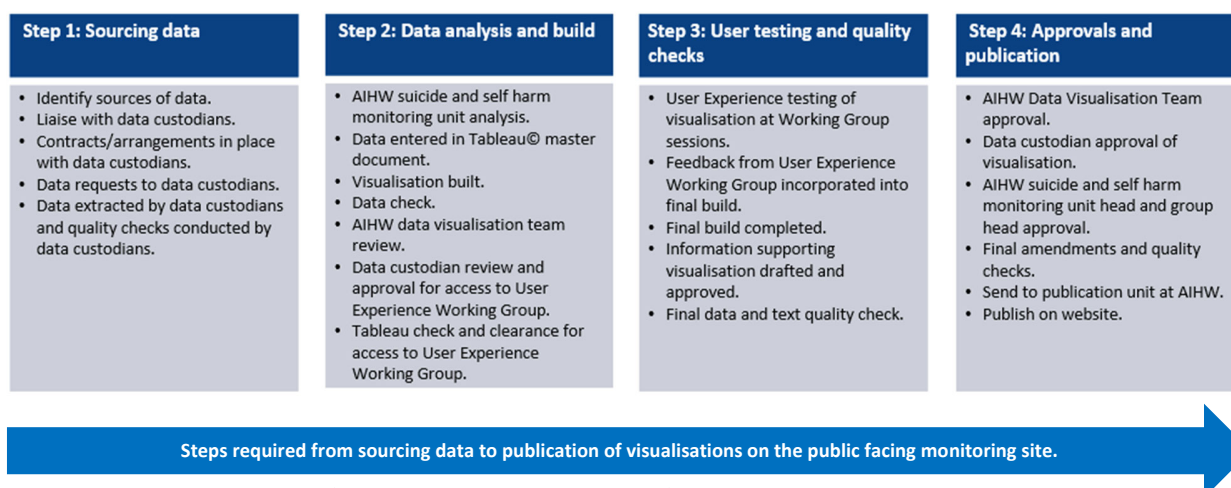


Figure 5: National Suicide and Self-harm Monitoring data processes for the Published Site.

The complexity of review, analysis and presentation of the data varied with the data sources and types. Across the Published Site, data from 10 sources were used to create the 37 visualisations and tables. Additional data were referenced throughout the Published Site in the descriptive information providing context for the visualisations and tables. Data that the AIHW commonly presents, such as the ABS Causes of Death data, were likely to have been simpler to process and present on the Published Site compared with data that required new relationships with custodians, bespoke analysis or data linkage. New analyses were conducted with a linked data project of the Multi-Agency Data Integration Project Extract, and linked

Personnel Management Key Solutions and National Death Index data 2001–18 (as described in Section 4.2.3.). Projects were co-conducted with other AIHW teams and external researchers for analysis of psychosocial risk factors associated with suicide deaths, analysis of Australian Burden of Disease Study data, and first-time coding and analysis of ambulance attendance data. These ground-breaking analyses likely involved significant complexity but will have paved the way for simpler repeat analyses to be conducted on updated data in the future.

Between the beginning of data processing in May 2020 and the launch of the Published Site in September of that year, 26 different types, and levels of checks and approvals were conducted on the data and visualisations to be reported. These were conducted by personnel within the unit responsible for the System, specific individuals within the AIHW, jurisdictional data custodians, data custodians of each source dataset, the User Experience Working Group, Everymind, the Department of Health, the National Mental Health Commission, and the EAG. The types of checks and approvals conducted included data accuracy and quality checks, technical note accuracy and completeness checks, general site structure checks, general site content and communication checks, and statistical reviews.

Considering the uniqueness of the System and complexity of the initial efforts to gather data, build the site, and secure relevant approvals, the Published Site was developed and published in a relatively short amount of time. The majority of data on the Published Site at launch represented deaths and hospitalisations up to 2019. Some visualisations only presented data up to 2015 while some were as recent as 2020.

5.3.5. Updates since the initial release

As of 31 October 2021, the Published Site contained 54 main visualisations and tables, 17 more than it did at initial release. The new tables and visualisations include additional data and analysis about suspected deaths by suicide from suicide registers, ambulance attendances relating to suicidal and self-harm behaviours, suicide deaths of Indigenous Australians, psychological distress during the COVID-19 pandemic, socioeconomic factors associated with suicide deaths, and international estimates of suicide deaths.

Between the initial release of the Published Site in September 2020 and October 2021, eight updates were released. These updates added more recent data to the visualisations, tables and information on the Published Site and included updates to data about deaths by suicide in Australia over time, international self-harm hospitalisations, Australian Defence Force suicide deaths, behaviours and risk factors, suicide and Indigenous Australians, ambulance attendances (for both suicide and self-harm behaviours), intentional self-harm hospitalisations by local areas, suspected deaths by suicide (from suicide registers), COVID-19 related data (including mental health service use, psychological distress, loneliness, suicide, and ambulance attendances), suicide by PHN areas, and international estimates of death by self-harm. Some of these areas of the Published Site were updated with more recent data at multiple time points.

These updates have occurred according to the published schedule and often within a week of updated source datasets being released by the data custodians. The process for review and approvals required to publish data to the site was split into two; one for new information or significant changes, and another for updating existing information. These processes are summarised in Table 2.

Table 3: Summary of the review and approvals processes for the updates to the Published Site.

	Process one	Process two
Update type	New information or significant changes	Updating existing information
Embargo required	Yes	No
Stakeholder email	Sent 10 days prior to public release	Sent 2 days prior to public release
Number of steps	19	7
Timeline	3 months	10 days
Purpose	Compliance, risk and quality improvement checks, subject matter review (internal and external), statistical review, Indigenous review, data custodian review	Compliance, risk and quality improvement checks, subject matter review (internal)
Completed by	Suicide and Self-harm Monitoring Unit, Unit Head, Deputy CEO, AIHW data custodians (Burden of Disease and Mortality Unit), Turning Point (Monash University), User Experience group (including people with lived experience, National Mental Health Commission, Department of Health), SCU statistical consultancy unit), Indigenous review, peer review, Everymind, Data Strategies and Information Unit, Group Head, Department of Health, National Mental Health Commission, EAG	Suicide and Self-harm Monitoring Unit, Unit Head, Deputy CEO

For both processes, the stakeholder email has been sent to Australian Government and departmental stakeholders (e.g., Department of Prime Minister and Cabinet, Department of Health, National Indigenous Australians Agency), state and territory health departments, state and territory justice departments, all PHNs, and various professional bodies and NGOs (e.g., the Australian Medical Association, National Aboriginal Community Controlled Health Organisation, Secretariat of National Aboriginal and Islander Child Care).

6. Semi-structured interviews

6.1. Our approach

We conducted semi-structured interviews with a range of participants across three defined stakeholder groups to assess the simplicity, accessibility, acceptability, and usefulness of the System.

- Group 1: participants who were involved in the design and development of the System and data custodians who had supplied data to the System.
- Group 2: participants who had engaged with the Published Site.
- Group 3: participants who had been involved in the development and use of similar systems in other countries.

Purposive sampling was used where stakeholders who met the inclusion criteria for each group were identified in consultation with the AIHW and added to a list of potential interview participants. Participants were recruited by email. The email invitation included information about the National Suicide and Self-harm Monitoring System, information about the evaluation, and a link to the online Participant Information Sheet and Consent Form. In total, we contacted 90 people and 44 participated in an interview. There were no incentives for participants of the semi-structured interviews other than the knowledge they were contributing to the development and implementation of a system that aims to inform and support suicide detection and prevention efforts within Australia.

The interviews were conducted between 23 November 2020 and 10 March 2021. Each one lasted approximately 30 minutes and was conducted via Zoom. We aimed to interview approximately 10–15 people per participant group for groups 1 and 2 (20–30 participants in total) and to continue data collection until saturation was reached (28) to ensure a diverse and complete range of perspectives were captured. We aimed to interview approximately five people in group 3 as there were very few similar systems in other countries and therefore few people who met the inclusion criteria for participation. We developed a unique interview guide for each group of participants based on their role or experience interacting with the System in addition to the attributes in the CDC guidelines for assessing public health surveillance systems. The interviews were audio recorded and transcribed verbatim, and transcripts were imported into NVivo version 12 for analysis. A thematic analysis was conducted using both an inductive and deductive approach. Thematic analysis identifies, organises and interprets patterns in qualitative data (29). Within each set of results (see 6.2 and 6.3) individual participants and quotations have been represented by a number (i.e., participant 1, participant 2 etc.)

6.1.1. Participant demographics for Group 1 and 2

There were 22 participants in Group 1 and 16 participants in Group 2. Due to the similarities in participants and interview guides for the two groups, the data from the two groups were analysed together (participants who were involved in the design and development of the System and data custodians who had supplied data to the System, and participants who had engaged with the Published Site). The results of 38 interviews are presented in this section. Group 1 included people involved in the design and development of the System and data custodians supplying data to the System. Participants included members of the EAG and User Experience Working Groups, representatives from the National Mental Health Commission, the Department of Health, the Australian Bureau of Statistics and state-based suicide registers. Group 2 included people who had engaged with the System as users of the Published Site. These participants included researchers, clinicians, journalists, suicide prevention educators, and representatives from NGOs, PHNs, local council and LGBTIQ+ advocacy groups.

6.1.2. Systems represented and participant demographics for Group 3

We interviewed experts who have been involved in the development and/or use of known international suicide or self-harm monitoring systems, to gain insights into attributes of these systems as well as any lessons learned along the way from working with these systems. They also offered advice on what they believed might further increase the use and utility of such systems to aid suicide and self-harm prevention and management in local communities and countries.

The results presented (see Section 6.3) from these interviews have supported the interpretation of results and recommendations for ongoing development and maintenance of the Australian National Suicide and Self-harm Monitoring System.

With few international examples of suicide or self-harm monitoring systems (and none that routinely bring both types of data together), we sought to interview key informants involved in the development and/or use of similar systems in other countries. Systems of interest were identified in the United Kingdom, Ireland, the United States, and Japan. Seven participants were recruited across six systems: the Bristol Self-harm Surveillance Register, the Oxford Monitoring System for Self-harm, the Irish National Self-harm Registry, the CDC Emergency Department Surveillance of Nonfatal Suicide-Related Outcomes and the CDC National Violent Death Reporting System both in the USA, and the National Police Agency Suicide Data System in Japan. Participants had worked in suicide and self-harm prevention for an average of twenty years, were psychologists, epidemiologists and/or researchers by profession, and they had mostly been involved in both the development and use of their respective systems over time.

Table 3 provides an overview of the characteristics of the systems included in the sample. Two systems collect suicide deaths data at a national level; the CDC violent death system that collects and links detailed information from numerous sources, including coroners and medical examiner reports, toxicology, death certificates and law enforcement reports and; the National Police Agency Suicide Data System which records information from police attendances for probable suicides across Japan and is known for timely but accurate data related to incidences of death by suicide. The other four aforementioned systems collect data on incidences of self-harm in emergency departments; three of these capture data within specified regions in a country and one system captures self-harm data at a national level. With exception of the CDC emergency department system, all systems have been in operation for 10 years or more, with the Oxford system being in operation for 45 years.

Table 4: Overview of the systems included in the sample.

System name	Data	Region/country	Year established	Data sources	Coverage
Bristol Self-harm Surveillance Register (30)	Self-harm	Bristol, United Kingdom	2010	Administrative and clinical data on presentations of self-harm to the Bristol Royal Infirmary and Southmead Hospital emergency department.	Population served by the Bristol Royal Infirmary and Southmead Hospital, Bristol.

Oxford Monitoring System for Self-harm (31)	Self-harm	Oxford, United Kingdom	1976	Administrative and clinical data on presentations of self-harm to the John Radcliffe Hospital emergency department.	Population served by John Radcliffe Hospital, Oxford.
The Irish National Self-harm Registry (32)	Self-harm	Republic of Ireland	2003	Administrative and some clinical data on presentations of self-harm to emergency departments as defined by the Registry.	National: all general and paediatric emergency departments in the Republic of Ireland since 2006.
CDC Emergency Department Surveillance of Nonfatal Suicide-Related Outcomes (33)	Self-harm	10 states in the USA	2018	Data on suicidal thoughts, behaviours and self-injury from the CDC's Emergency Department National Syndromic Surveillance Data Bio Sense Platform.	10 states in the USA; Louisiana, Maine, New York, Ohio, Oregon, Rhode Island, Utah, Vermont, Washington, West Virginia.
CDC National Violent Death Reporting System (34)	Violent deaths including suicide	50 states in the USA, the District of Columbia, and Puerto Rico	2002	Gathers and links data from several sources, including law enforcement, medical examiners, coroners, toxicology, and death certificates.	In 2002, six states participated. In 2006, 17 states participated and now this system is implemented in all 50 states, the District of Columbia, and Puerto Rico.
National Police Agency Suicide Data System (35)	Suicide	Japan	1978 with co-publication with Cabinet Office since 2011	Police investigations of all suspected suicide cases across Japan.	National: all police attendances across Japan.

6.2. Group 1 and 2 key findings presented in themes

The results of the interviews are presented as themes within each of the attributes outlined in the CDC Guidelines for Evaluating Public Health Surveillance Systems (22) plus an additional two categories for data custodians and ongoing system improvements.

Table 5: List of themes from semi-structured interviews for Groups 1 and 2.

Attribute	Theme
Simplicity	Simple system for complex data
	Ease of navigating the System
	Data in a single place
	Simple summaries of data for users
	Data gaps are not communicated
Accessibility	Structure increases accessibility
	Difficulties in finding specific data
	Knowledge of data availability increases accessibility
	Accessible data is interpretable data
	Increase in accessibility of data for all data users
	Ongoing engagement with users to improve accessibility
Acceptability	PHN and other organisational engagement with the System
	Balancing the need for information versus sensitivity
Usefulness	Media engagement with the System
	Controlling the suicide and self-harm narrative
	Evidence based prevention efforts
	Detection of suicide and self-harm
	Timeliness versus accuracy for detection
	Prevention of suicide and self-harm
Additional themes outside the CDC attributes	
Ongoing System improvements	Appendix of data sources and data timeframes
	Timely data
	Data pertaining to sub-groups who are over-represented in suicide and self-harm statistics
	Assisting users of the System to use the data appropriately
	Direction to further analysis of the data
	Hospital data presentations
	More data on self-harm
	Future data linkage potential
	Ongoing feedback from users of the System
	Voluntary assisted dying
	Ongoing communication about the System
	Responsibility for responding to trends that are identified

	Lived experience contributions to the System
	Transparency of access to non-publicly available data
Data custodian perspectives	Standard practice for some custodians
	Resource intensive for custodians who don't usually report
	Routinisation of processes
	Intrinsic sensitivity of the data
	Supporting a national network of data custodians
	Communicating with custodians about the uses of data
	Links for System users to get further information
	Positive experiences working with AIHW

6.2.1. Simplicity

Simplicity refers to both the structure and ease of operation of the System. During the interview, participants were asked questions about whether the System had been structured in a way that allows for ease of operation, what elements of the System were easy or complex to operate and if they could think of any advantages and disadvantages of the design of the system.

6.2.1.1. Simple system for complex data

Participants noted that the System is set out in a way that makes it user-friendly for a broad range of users, including those who want access to high-level summary data and those who want access to more complex data.

Participant 6: *"I think the way the website is set out, yes, I think because they have summary statistics and sort of high-level information for people who aren't data savvy. And then for those who are, they can delve into the different datasets in more depth."*

Data savvy users of the System, such as researchers, indicated that the System is set out in a way that allows them to contextualise specific issues related to suicide and self-harm that they are researching.

Participant 24: *"[...] every researcher has to contextualise the problem they're facing, and these indicators are exactly that and it's a very succinct and comprehensive sort of collation of all these indicators that we need to be keeping an eye on and it gives us a good sense of trends."*

6.2.1.2. Ease of navigating the System

Participants discussed the ease with which they were able to navigate through the System and made reference to the System's ability to support policy makers and community members in suicide prevention strategies.

Participant 4: *"[...] it's actually quite easy to navigate through. It is quite descriptive, and it adds a lot of context around information from how they collected the data, what it means [...] I think it's quite user friendly"*

and I think it would be able to support policymakers and people in community I suppose in suicide prevention to inform their strategies.”

6.2.1.3. Data in a single place

Participants discussed that having a single System for multiple sources of data – including new data that were not previously available or only available to those who knew where to look – was an advantage.

Participant 8: “[...] it's all in one place and then you can find it, so you don't have to be going looking in different places for it, is I think that's the big advantage that's brought it all together. So, for me that's the real bonus, because prior to the existence of the website, you know you had to go and look for data all over the place. And, the other thing is that there's new data there, so for instance the ambulance data from Turning Point, all those kind of things are quite innovative and novel in the sense that they weren't readily available before, so it's all been brought together in the one place you can find it.”

Participant 13: “[...] a lot of this stuff was already available from other places, but you needed to know where to get it from... some of the self-harm stuff [...] you almost needed to know who to ask in order to get it. It's great to have this as a central [...] clearing house, and hopefully it'll become more complete over time.”

6.2.1.4. Simple summaries of data for users

Participants noted that summaries of “what the data says” make it easier for some users to interpret the information in the System. They stressed that maintaining summaries would be useful and made specific reference to summaries that contain information on a “snapshot of suicide”.

Participant 12: “[...] updated summaries of what the data actually says, those high level points will be important to make sure that's maintained because sometimes people are – some people will be going there just to look for the most recent updated kind of snapshot of suicide, because again maybe [it] is not always immediately interpretable when you're just using the cause of death data and their summaries are not necessarily the summaries [you] are looking for – so I think some attention to keep focus on what summaries people might be looking for would be useful.”

6.2.1.5. Data gaps are not communicated

Participants commented that the System does not communicate what data are not available, citing this as a disadvantage. They made specific reference to lack of communication about gaps in data for LGBTIQ+ and Indigenous populations.

Participant 1: “And a disadvantage is that it's very difficult for the system, the website to show what it can't show, the limitations of the system is very difficult to kind of illustrate, so that's one of the I guess the risks – people going to the website they may think that this is exhaustive when of course it's not and it's hard for the website to communicate with data that's missing, so for example there's a lot of information we would love to include over time, relates to specific cohorts like LGBTIQ community, data regarding Aboriginal and Torres Strait Islanders communities – some of their data's not there and it's hard for us to kind of communicate that that data is missing.”

6.2.2. Accessibility

Accessibility refers to the availability and ease of use of data within the System to support an understanding of suicide and self-harm. During the interview, participants were asked questions about whether the System

increased the accessibility of data, what they thought was easy or more difficult to understand and whether there was anything they couldn't find within the System that they were looking for.

6.2.2.1. Structure increases accessibility

Participants discussed how the structure of the website makes it accessible. For example, one participant mentioned that the System is more accessible than other government websites which may require more technical knowledge to navigate.

Participant 9: *"[...] we've used it a lot and distributed information about it to many of our users in New South Wales, and you know, I think it's a very nicely structured, very accessible website, and I mean AIHW has a lot of good data on its website, some of their sites you know can be – you need a lot of technical knowledge to know what you're navigating to, so I think this has been carefully designed to be a step more accessible than some of the traditional government data websites, and certainly I think it strikes a good balance of making data easy to navigate to and clearly presented, you know but still having detailed information and that ability to kind of drill down or download data – so you know, I think it's well structured."*

6.2.2.2. Difficulties in finding specific data

Participants discussed some of difficulties in accessing data that they knew were in the System but that they couldn't find easily.

Participant 22: *"[...] my experience is there was stuff that I knew was in there that I couldn't find so I couldn't find the interactive maps very easily, I don't know whether that's me or design of the website but I think there might be things where you have to click to be able to get there ..."*

6.2.2.3. Knowledge of data availability increases accessibility

Participants discussed that some users of the System would have known about and had access to the data prior to it being launched and other users wouldn't have known about the data. They noted that for the latter group of users the data are now more accessible.

Participant 3: *"[...] for researchers who know about all these datasets it probably, I mean it's helpful just to know it's all in one spot, but it doesn't actually increase access because a lot of this was available. But for the general public, and for people who don't have detailed understanding of the different data sources and where they come from, it's excellent."*

Similarly, participants spoke about the need to raise awareness about the data to enhance its accessibility.

Participant 10: *"If people don't know it's there, they won't use it. I think that's going to be the challenge, is getting the PR that this is available now. Other than that, I actually don't see an issue of people not using it, it's them knowing that it's there, because for so long we've had nothing."*

One participant said that they weren't aware of the System and said that if there was more awareness, there would be more uptake.

Participant 36: *"I think I was kind of surprised that I didn't know about it and so whether or not it can be promoted a little bit better, that might be an oversight on my end but you know I think I was a bit surprised when I went oh I didn't even know this existed [...] if it can be pushed a little bit more I think you'd get a greater uptake from everybody."*

6.2.2.4. Accessible data is interpretable data

Participants indicated that they thought making the data accessible was the right thing to do. However, they discussed the fact that in addition to making the data accessible, it was also important to make them interpretable.

Participant 22: *"[...] there's debate as to whether it's good to release data to the public or not. I probably think it's better to release it than not release it because without it, people just speculate and make things up, potentially. Or people just rely on their perceptions of there seemed to be more suicides occurring than previously, and I don't think those perceptions are reliable. So, I think it's a good thing that the data's been released, probably people just need help in interpreting it."*

6.2.2.5. Increase in accessibility of data for all data users

Participants reflected on the fact that even for those users of the System who knew about the data prior to its released, the collation of data in one place with the addition of new data increases the overall accessibility of the data.

Participant 5: *"It's collating data from many, many different sources that in some aspects some of it was publicly available before but you had to go here, and you had to figure out this, find this and then you had to go here, and you had to find this, and then individual states have their own sort of little things going on so bringing all that together in one place as well as adding new analysis in a way that fleshes out that whole picture is a huge improvement in that space."*

Participants who work at NGOs noted that for those with less access to data prior to the System being launched, it made the data more accessible.

Participant 23: *"I'm so excited that this is happening I think it's great you know I think it's probably because we're coming off such a low base of data in Australia anything was going to be good right but even with that sort of acknowledged I think they've done a cracking job, I think it's really good, I find it very accessible you know it's laid out in a way that you can find what you need, there's nuanced data there. I think it's great."*

6.2.2.6. Ongoing engagement with users to improve accessibility

Participants discussed the need to engage user groups in conversations about suicide and self-harm. As an example, one participant spoke about the need to engage young people in conversations that inform the ongoing design of the System to ensure that it is accessible to this user group.

Participant 19: *"[...] my overarching comment I guess I can only assume that people are still scared and fearful about engaging young people in discussions about suicide and particularly around this sort of information and I think that's disappointing given it's a national project and should be people know how to do it well, people like Orygen obviously know how to do it really well in engaging young people – so I think that's still a gap in terms of it being accessible."*

6.2.3. Acceptability

Acceptability refers to the willingness of people and organisations to participate in and use the System. Participants were asked questions about whether they thought external organisations (such as PHNs, NGOs and other organisations who work in suicide and self-harm prevention) would be willing to interact with the System to inform their prevention efforts and whether the 'sensitive nature' of certain data, such as the reporting of suicide methods, was adequately catered for.

6.2.3.1. PHN and other organisational engagement with the System

Participants indicated that they thought PHNs would engage with the System, especially because they had been consulted with during the System's development phase.

Participant 5: *"They will, they absolutely will. There are a number of analyses in there that were specifically catered to for Primary Health Networks, and they were consulted as part of that process about what would be useful to them you know they were engaged long before the end of the project and shown preliminary workups of things and I remember the feedback from those workshops as very positive so they will absolutely be using that for that purpose."*

Participant 25: *"It will help it will be a very useful tool for Primary Health Networks absolutely not only from a needs assessment and planning perspective but also as a way to start narrative and discussions around cross-jurisdictional joined up services as well and their prevalence that would be really important. I think obviously the trend data and the fact that it is so simple that will be great for analysis and also great for conversation to move forward."*

Some participants noted that PHNs may not be able to access the information that they need for their prevention efforts.

Participant 19: *"If they can't kind of drill down to their little local patch and really understand what's happening it will become just another website that nobody goes to – so I think that's going to be the challenge – it's really you know we've got a starting point."*

Participant 3: *"[...] they might find themselves going okay this is great, but I want to know specifically about my area. So if there is, if that data is available but it's just not in this system, because you can't have every cross tab and you know you can't have a graph for every single individual LGA or PHN, that yeah maybe if there was links to say if you want data for your specific area, you know, as long as there's somewhere for people to go if they're interested in their particular data – if that is able to be released – then I think they'd use it even more."*

Other participants noted that PHNs may want access to specific data but explained that there are complexities involved in providing these data that make it difficult to implement in the System.

Participant 8: *"[...] sometimes PHNs and like organisations come with a sort of menu and say well you know why isn't this possible in 2020, and you say well because there's information systems that underpin all this and you know there's not a master dataset, and the thing that people often lose sight of is that lots of the data is a by-product of other activities."*

Participants also highlighted the need for PHNs and other organisations with responsibility for responding to suicide and self-harm to access the Portal to ensure that they have the right level of information to inform their prevention efforts.

Participant 12: *"I also think that obviously there is further work that needs to be done around who gets access to the back-end system, so obviously there is the publicly available kind of system at the moment and then there's the back-end secure portal that's being worked on, but certainly having worked in the region and having worked closely with PHNs it is critical that PHNs – and not just PHNs, other people who are responsible for co-ordination of local suicide prevention efforts and suicide prevention activity in a region, do get access to best available data and they get that at the regional level, not just at the national level, we know that we've got variations across regions and actually patterns of suicide behaviour look different, patterns of hospital presentations, patterns ambulance presentations and callout and they all look a bit different and also risk*

factor data can look a bit different in different regions as well, partly based on the kind of demographics of those regions.”

Participants discussed that LGBTIQ+ advocacy organisations which have a significant role in suicide and self-harm prevention currently don't have access to relevant data within the System to inform their prevention efforts.

Participant 26: *“[...] it's just important to kind of highlight that you know we have some of the highest rates of suicidal behaviours and it's just like we don't want like we just need the data to actually see a reduction in those disparities, it's not something that we just want because it makes us feel good we actually desperately need it in order to advocate governments and policy makers to have some like national coordination and targeted responses to sort of see this change because as I said before its remaining the same and our health disparities are getting worse in some areas and a key to fixing that is good data.”*

Participants discussed the fact that that the System doesn't provide sufficiently fine-grained information to guide local councils as to where they should target their suicide prevention efforts.

Participant 38: *“Certainly for us, from a geographic level, breaking it down further into where possible a suburb level. Because the [council area] straddles several headlands which have unfortunately become hot spots, we're losing more off multiple headlands than we ever have before. We used to have just really one hot spot location, now we've got probably five headlands that unfortunately have been used for death by suicide, and we know that from the raw data, but being able to actually pinpoint it from this data source, would actually be really helpful as well. It can also help us as well if we wanted to put in for funding submissions to put new fencing on a headland area, which we know has been utilised significantly or is trending upwards. Because putting up fencing costs thousands and thousands of dollars to do the inward curving fencing, you know which is best practice for suicide, for harm minimisation. We just don't have that money to do it unless we can actually justify it by the use of data really.”*

Participants who work for NGOs discussed that at a general level, they are able to use the System to ensure that their work in suicide and self-harm prevention is based on the latest available data.

Participant 23: *“I use the website to get current data to write into policy submissions to make sure that whatever we are recommending is based on the latest data. So, that's the sense in which for the policy work that's primarily why I use the AIHW site.”*

6.2.3.2. Balancing the need for information versus sensitivity

Participants were positive about the fact that the System provides more 'self-care' messages than other government websites.

Participant 2: *“[...] the ABS even with its best efforts in its way of presenting data has not really given as much attention to the warnings and the self-care messages as the AIHW system now can and does do so it's an improvement.”*

Participants also highlighted the importance of the balance between informing participants about the sensitive nature of the data and making the data available for prevention efforts.

Participant 3: *“I clicked on the about methods, and I saw that, not a warning, but something comes up at the top saying basically do you really need to look at this information. And I think that's good, I think that's good that it's there. But, I also think it's good that the data is available as well, because it's important, I know*

there's a lot of sensitivity about what methods people use [...] so I think they've got the balance right, because they've got the warning, so if you know that that's not something you really need to be looking at, you can look away. But if it is something that you're interested in, which people are interested in for prevention, I think they've got the balance right from what I could see."

Participants also discussed the importance of including the information about suicide methods so that it is available to increase understanding suicide trends and inform prevention efforts but, at the same time, ensuring that it isn't highlighted or included in summary pages.

Participant 17: *"[...] that was something that we really struggled with during the working groups and you know there was some discussion about do we really need to have a breakdown very explicitly of methods but at the end of the day I guess for the robustness of the system it had to be there, so you know I was actually on there a couple of days ago and I love now that they've put some very clear warnings and cautions before you go to certain parts of the site, so I am hoping that's enough of a warning particularly for people with lived experience who will not go to that data if they don't want to, I think that's the best you can do – if you want a complete dataset which includes that kind of data then all you can do is really put protections around it."*

6.2.4. Usefulness

Usefulness refers to whether the System can contribute to the prevention and management of suicide and self-harm, including by improving understanding of the public health implications of suicide and self-harm. Participants were asked about whether they thought the System is capable of reporting on suicide and self-harm and contributing to prevention.

6.2.4.1. Media engagement with the System

Participants saw potential in media professionals engaging with the System to write data-driven stories that could encourage responses to suicide and self-harm by governments. However, participants also noted the potential for media professionals to sensationalise the data from the System when framing a local story.

Participant 7: *"It's been interesting seeing how the media has used the website and I think for instance our local media here really drilled into the very local data and kind of framed a story that was quite sensationalised around that but by the same token those kinds of conversations at a local level I think can be helpful to push along you know community consensus that this is an important issue and community activities that we need to do more, be involved in these activities, help fundraise and also to not prevent government from wanting to undertake these activities."*

6.2.4.2. Controlling the suicide and self-harm narrative

Participants mentioned that having a System of comprehensive, publicly available data means that there is potential to 'control the narrative'. They noted that the AIHW can contribute a data-driven perspective on suicide and self-harm and not have to rely on other organisations accessing data and making inferences that could be sensationalised. They commented that there are influential commentators who shape public views, and that one of the benefits of the System is to help ensure that the narrative is evidence-based'.

Participant 20: *"[...] it has an opportunity to draw on the evidence and do it in a measured way because again this sort of stuff develops a life of its own and the media loves it and there's predictions of this terrible, terrible increase in the suicide rate which would be awful and I really hope it doesn't happen but there's mixed evidence and there's some really good papers from you know previous economic downturns that we've drawn on and so I sort of feel like the AIHW is a position to you know contribute to a more balanced view [...]* This is

an opportunity for a trusted sort of government agency to take a more measured approach and that would be a really good thing.”

6.2.4.3. Evidence based prevention efforts

In a similar vein, participants discussed the fact that the availability of data will help make prevention efforts more grounded in evidence.

Participant 2: “[...] because we haven’t necessarily made the data available so widely in the past there’s been a lot of speculation and hearsay [...] There still is in our media and unfortunately by some people who should know better, and it misleads people, and it sends us down burrow holes that are not helpful and ultimately you know we haven’t got that much time or resources to be going down unhelpful or misplaced burrow holes on suicide prevention that we need accurate data, and it will help us direct our efforts to those who we can reach out to and should [...] the utility of this monitoring of data system I really believe will be a game changer in suicide prevention.”

6.2.4.4. Detection of suicide and self-harm

Some participants discussed the ability of the System to help with the detection of suicide and self-harm. They noted that timeliness of data is imperative to accurately detecting suicide and self-harm and expressed disappointment that the data are not generally ‘real-time’. However, they also noted that even with time lags the data would be useful for organisations such as PHNs to see how their local area compares to other areas.

Participant 3: “[...] the detection, ideally I think people thought that this was going to be like a real-time monitoring system, and there might be plans for it to be like that eventually. So, in terms of like detecting if there’s something going on in a particular area, no, it wouldn’t be useful for that, because it’s not real-time data. But in terms of communities and you know people who work in health or PHNs being able to look at data and see how their area relates to other areas, I think then that can be useful.”

Other participants discussed that in addition to real-time data, detection would require analytical work to identify patterns or clusters and after this identification, there would need to be an organised response to any trends that are identified.

Participant 21: Detection I think is harder because it’s got to be timely, which means the data has to be coming in in a timely way and that’s sort of one challenge and that’s potentially doable – but then it has to be analysed and there sort of needs to be an alerting sort of system so there needs to be people on standby really to be able to you know if a pattern emerges in the data that suggests that there might be a cluster happening or a trend happening, that analysis or algorithm or whatever has to find that but then there has to be someone to respond to it and so structuring the user community, the users in a way that there is a pathway for something to occur when detection happens, I think that’s a little bit more of a meticulous or complex system that has to sort of be crystallised in place for that to happen.”

6.2.4.5. Timeliness versus accuracy for detection

Participants discussed the trade-off between the timeliness and accuracy of data and suggested that the System represents a major improvement in both. Nonetheless, some participants warned that System users may be disappointed because they may have had expectations of greater data timeliness.

Participant 2: “If it comes down to it, I’d probably back a trade-off of doing more reliable data against recency or currency and that trade off will continue to shift through...I think most people will find this is a really big step up. There will be some who because of their expectations may be disappointed with where it is right now

and there will be some who will probably never meet their expectations within what's reasonable but on balance, I think it's pretty good."

6.2.4.6. Prevention of suicide and self-harm

Some participants commented that the System will be able to contribute to evidence-based policy decisions, especially in terms of defining the problem and identifying the risk factors for suicide and self-harm. In their view, this will undoubtedly aid prevention.

Participant 21: "[...] definitely prevention, it'll be able to contribute to prevention – I think the amount of information that's going to be brought together will make it easier for policy makers and planners to engage with the evidence, and because I do think certainly in government, the evidence does matter, but you know being able to describe the problem and describe the risk factors does inform policy decisions. So, it's got a lot of potential to contribute to that."

One participant suggested that offering information about how the data will be used for detection and prevention would be helpful.

Participant 30: "I think there needs to be something a little bit clearer on the use of the data and how and why it is helping with the connection to suicide prevention."

6.2.5. Ongoing System improvements

6.2.5.1. Appendix of data sources and data timeframes

Participants mentioned that having an appendix that lists all the data sources and the time frames for which data are available would be helpful. For example, one participant spoke about being able to make better use of the System if they knew exactly what data it housed.

Participant 29: "[...] for me as a researcher, from my perspective, the ability for it to speak to what data collections are available over what collection periods would be really useful for me, for the purposes with which I would usually be accessing this data collection or this system."

6.2.5.2. Timely data

Participants discussed the fact that it would be useful to incorporate real-time data into the System. As an example, one participant referred to the marriage equity debate and the value of being able to see the impact on at risk populations such as the LGBTIQ+ community during a specific time period. Participants also discussed the fact that, whilst the data in the System from suicide registers and other data sources are world-class in terms of being close to real-time, other data such as hospital admissions and emergency presentations would be useful to have in real-time too.

Participant 1: "So when for example there is say a marriage equality debate, we can actually look at the data month by month for LGBTIQ+ communities, I mean that would be really valuable, we're not quite there yet, but we'll get there."

Participant 15: "[...] the fact that we're still not getting real-time information – particularly around attempts and other things like that through the hospital and health systems and the Local Health Districts... so even though we have pieces of work which look at a national level at certain periods of time and where it's been reported and coded etc, we're still not getting real-time stuff and I think that that's an area for improvement."

6.2.5.3. Data pertaining to sub-groups who are over-represented in suicide and self-harm statistics

Participants commented that the System would be improved by having specific data on LGBTIQ+, Indigenous populations and culturally and linguistically diverse (CALD) communities.

Participant 17: *“so one of the limitations that I think is there, but I’ve noted they’ve got it on the project plan, is to address moving forward there’s no data capture for LGBTIQ people.”*

Participants highlight that capturing data on Indigenous populations is especially important if the System is going to be used to inform policy and decisions about funding priorities.

Participant 15: *“we have to be really mindful of what we’re doing with regards to ensuring that we do have Aboriginal and Torres Strait Islander people included in the information that’s recorded and potentially you know I think that there’s a need for reform in some of that stuff, even at a higher level and you know how we’re capturing regions and areas so that information can still be reported, because it then becomes under reported, and when it’s being used in things like to inform policy or where they should be prioritising funding for and different things like that or responses or if there is a critical gap – we’re still not included and I find that really challenging.”*

Participants highlighted that capturing data on LGBTIQ+ populations is important for informing specific suicide prevention interventions and that at present, the System isn’t as useful for these populations as it doesn’t provide the information that these advocacy groups need.

Participant 26: *“It’s a good question and well to be upfront I think it doesn’t really have much purpose for us I guess because as you probably know we don’t actually have LGBTI indicators in suicide death data records and coronial report data and that is a real issue for us so whilst it’s important that we engage with this system unfortunately, it doesn’t capture our populations and a lot of people are surprised when we tell them that we actually don’t know how many LGBTIQ+ people die by suicide each year in Australia but of course we know that you know some of the large studies undertaken on our community show that we have disproportionately higher rates of suicide or behaviours so that kind of then lends itself to the assumption that we are over-represented in suicide statistics. We’d love to utilise it but unfortunately because those indicators are not embedded in the data sets then we actually can’t use it in order to yeah like you say you know provide evidence when we are looking at you know specific targeted interventions for LGBTIQ+ people in suicide prevention.”*

Participants highlighted that whether someone comes from a CALD community is an important indicator for suicide and self-harm and would be useful to include in the System.

Participant 33: *“I would say a bit of focus needs to be given to CALD communities and definitely because the incidence of stress [...] is not very well addressed so I think that’s important because they are a huge part of the Australian community.”*

One participant made a more general point when they mentioned that more information about ‘who’ (age, gender, ethnicity) is dying by suicide would be helpful to their suicide prevention efforts. They noted that they have had difficulties accessing these data in the past as it has been cost prohibitive and would be useful if it was available in the System.

Participant 38: *“having more of the ability to be able to break down the numbers, per age, for gender, maybe even ethnicity, but I don’t even know if that’s even possible, because I tried to do that with the NCIS data and*

they were saying that that would've meant they would've had to manually manipulate the data, which would've been hugely expensive, and I just couldn't afford that cost. So, I guess really knowing who you're losing is probably the biggest thing that I feel that we need help with, so that local communities can actually direct their interventions appropriately, and that we're actually on the money when we're trying to you know design preventative campaigns or primary prevention campaigns, who do we target. So that's the kind of level of detail that I think would be really helpful from a local community or local government perspective."

6.2.5.4. Assisting users of the System to use the data appropriately

Participants noted that there is a need to ensure that people use the data appropriately and made specific reference to media, commissioning agencies and service providers.

Participant 1: "I think there's still a lot that we can do around how people can use the data, so the public website ... its main function is to provide data and make that data available to people, I think that's doing that job really well and we'll get better at it, but that's only half of the equation, the other half is around trying to make sure that those people who go to the public website and access that data, that they then use it well, they use it responsibly and they use it effectively and that goes for media as well as commissioning agencies or service providers, or people in the general community who are wanting to contribute to suicide prevention."

Similarly, participants made specific reference to journalists needing assistance to interpreting and using the data appropriately.

Participant 28: "when you are just looking at the bare bones data, and I mean that's what the data's here for it's meant to be bare bones, but the issue with that is that it is subject to the interpretation of the journalist and journalists are always looking for trends in stories in data to inform their stories so I do think that it's probably important to have some kind of disclaimer in relation to how the data's interpreted just to make sure that there aren't generalisations."

6.2.5.5. Direction to further analysis of the data

Participants discussed the value in continuing to include analysis data from other sources outside the AIHW.

Participant 2: "in the start-up of the System there have been included pages with links to research studies using the data you know which provide I guess some analysis and explanation and I really like that I think that is a really good feature and I hope that that will continue i.e., for high quality data analysis that it's reported with some explanation by credible sources as has been done in this case such as the ANU is really part of making the data accessible and I know that at one level we might say just report the facts, just give people the data, because I'm a data user I tend to go more on the side of go a step extra, put a little bit more in that helps people understand the data. Don't just give them the facts and leave them to try and work out how to understand it, give them a little bit more."

Similarly, participants discussed that including research would be useful to their needs in suicide prevention. As an example, a participant from a PHN that uses the System to inform their prevention efforts said that it can be hard for PHNs to be across the latest academic research in the area.

Participant 37: Look some sort of synthesis of research concerning the effectiveness of different types of interventions would be really useful for people in my type of role [...] And I think it could help inform the sector more broadly as well [...] unless you're moving in and out of academic circles it's hard to get your hands on that sort of stuff ... some of those reports which can sit alongside of the numerical data."

6.2.5.6. Hospital data presentations

Participants described the need for data to be included about emergency department presentations for self-harm.

Participant 3: *“There's also no information about emergency department presentations, which I know is complex because not all states and territories have emergency department collections where you can identify self-harm [...] I think there's a bit more data that could be included.”*

One participant highlighted the importance of hospital emergency department data for self-harm that may not be picked up elsewhere, especially if individuals are not admitted to the hospital and instead, referred other services.

Participant 5: *“people are hurting themselves and they're turning up in our hospital system and notably they would usually go the emergency department first. An incident of self-harm for example, even if it's minor it will usually end up in the emergency department first but let's just say it was minor in a physical sense then that patient might not be admitted to the hospital, they might receive some care in the emergency department and then be referred to other services, social services and this kind of thing and never be admitted into the hospital system and that currently is not available anywhere in the national picture.”*

6.2.5.7. More data on self-harm

Participants discussed the fact that including more detailed information on suicide attempts and self-harm would be helpful in suicide prevention efforts. One participant noted that suicide data is useful but the opportunity to prevent suicides by picking up on earlier self-harm behaviours – including those where the intent is suicide and those with other intents – would be helpful for prevention.

Participant 2: *“to be able to have some visibility around behaviour such as suicide attempts or even you know self-injury that may not technically be classified as a suicide attempt, to have some indication of where people are disclosing their suicidality and suicidal crisis and to have some picture of you know who they are and where they come from and what are the factors, all this is vital intelligence to planning our service responses and our longer term preventative work. I mean the data around suicide deaths is important but it's always a bit too late. We need the data around people who are experiencing elevated suicidality in their lives or elevated distress even if we're really going to be more effective in prevention.”*

6.2.5.8. Future data linkage potential

Some participants expressed a desire to be able to map out the ‘journeys’ of people who have been suicidal. Some noted that for this to be possible, data linkage was required.

Participant 8: *“The challenge still is to tell the journey, so trying to actually see where folk might go if they've got suicidal ideation or you know suicide attempt or whatever, that's the challenge in terms of telling the story of what's going on, what the data can tell you. So, I think that could be something that we could revisit and see whether or not we could do that in a better way so that you had an understanding at a glance what was going on. Because currently they're a bit disconnected.”*

Other participants described the potential for future data linkage to understand risk factors for suicide and self-harm.

Participant 11: *“an area where I think there's probably quite a lot of fairly untapped potential but that's not again not yet really evident in the system at least when I had a look at it a few months ago, is information*

based on record linkage systems so it seems to me that there is a lot of potential in the sort of medium term to better understand risk factors, consequences through a variety of kinds of record linkage projects.”

6.2.5.9. Ongoing feedback from users of the System

Participants felt that the System would benefit from ongoing user feedback.

Participant 10: *“I think the more of us that input into it as users the more of us that use it, and give feedback, I think any system is only as good as the people that use it and are willing to offer feedback and to develop it, and to help it develop and grow.”*

6.2.5.10. Voluntary assisted dying

A participant commented on what they perceived as a link between voluntary assisted dying and suicide and self-harm. Voluntary assisted dying is outside the scope of the Project and System.

Participant 11: *“One other kind of neighbouring construct that again is hard to study but can be studied is kind of end-of-life euthanasia with a doctor assisted or otherwise hastening of death you know, and you know we’ve had a few brushes with legalisation of versions of euthanasia or medically assisted or medically advised euthanasia you know it’s a class of you know a type of cause of death that is conceptually sometimes quite close to suicide and sometimes not. It’s a bit difficult because of the grey or black legal status of it but then all suicide was illegal only a few decades ago and it sort of seems to me that there are probably sort of enough threads in common between that and the kind of actual self-harm and suicide that is very definitely in the scope of this project to warrant at least some kind of consideration.”*

6.2.5.11. Ongoing communication about the System

Participants discussed how there is a need to communicate to System users when new data have been released and what they mean.

Participant 12: *“[...] there’s probably a piece that could be done over the top of it which is like – almost like a knowledge translation piece that as new data comes up, synthesising what that means – taking an historical view not just what the data – the new pieces of data mean [...] regular communication so people don’t have to go and access it themselves, that the system itself also generates [...] new knowledge and new information for people so that it kind of – it’s that push pull thing of pushing information to people who need it, not just ensuring that they’ll come into the site to get it.”*

6.2.5.12. Responsibility for responding to trends that are identified

Participants discussed a need for oversight of how patterns of self-harm and suicide are responded to. For example, some suggested that if there is evidence of self-harm and suicide in specific areas, those responsible for suicide prevention in those areas need to be alerted so that they can respond.

Participant 12: *“[...] if we can pick up patterns of self-harming behaviour and presentations and patterns of suicide attempt in the regional level and we see those patterns and we do nothing about alerting those regions or having conversations around what does that mean about what might be coming, then the system’s not informing suicide prevention practice, it’s just a system of collecting better data.”*

6.2.5.13. Lived experience contributions to the System

Participants with lived experience of suicide who had been involved in System design and development expressed a desire to know how their feedback had been incorporated. Alternatively, if their feedback hadn’t

been or couldn't be incorporated, they wanted some information about why this may not have been possible.

Participant 16: *"So once again I'm not sure how relevant lived experience is to a lot of this, other than the final presentation, I am not sure how much notice was taken of what lived experience had to offer, and I do not see that there was any feedback process whereby if you said 'X' would be a neat thing to have, nothing came back to say whether 'X' had been discarded for the following very good reasons, or X had in fact been included."*

Other participants with lived experience noted that they thought their feedback had been taken on board and implemented into the System.

Participant 17: *"I love that they actually took on board all of the feedback from us – people with lived experience about how they could improve both functionally and in terms of ease of navigation etc, so yeah I think it's a good system."*

6.2.5.14. Transparency of access to non-publicly available data

Participants noted that having a transparent process around who gets access to the non-publicly available data housed within the System would improve the current situation for data users who describe having issues with data agreements with state and national suicide and self-harm data custodians.

Participant 29: *"[...] you think you've got an agreement or, you think you've got a process in place, and the goalposts just seem to change quite frequently. And, you really can't do research like that, you know, there needs to be a process which is transparent, whatever the process is, there's got to be a process which is transparent, which you tick all the boxes, and then you know you get your ethics or whatever it is you need for your agreement, and then the agreement is executed. You can't have this situation where you've proposed a project, you've even secured funding for it, you've got ethics for it, and then at the last minute you can't get access to the data you thought you were going to get access to. So, I've found that incredibly frustrating, and I think that's something that hopefully can be improved going forwards."*

6.2.6. Data custodian perspectives

Data custodians were asked the same questions as the other participants. In addition, they were asked some specific questions about whether the System had been set up in a way that allowed for ease of participation as a data custodian, and whether they could identify any things that would make their participation difficult or easier.

6.2.6.1. Standard practice for some custodians

Data custodian participants discussed that it would be useful to have a 'statement of the rules' so that different custodians have a clear understanding of their obligations. One participant used 'self-suppression' of identifying information as an example of a useful standardisation.

Participant 8: *"the thing that is always a bit tricky in this space is having, and I'm not sure whether or not they do so, is a clear unequivocal statement of the rules. So, for instance, self-suppression and things like that, so that they are known and shared. Because often what you find is that different data custodians and data stewards have different rules, and so that makes life very tricky. So, I think that would be the – if you know what you are supplying data to and what the rules are, then makes life a lot easier, and sometimes that's not clear."*

6.2.6.2. Resource intensive for custodians who don't usually report

Data custodian participants discussed that one of the limitations of their involvement in providing data to the System is they often need to provide data to other initiatives, such as domestic violence data collection efforts, all of which are resource intensive.

Participant 18: *"We have very finite resources here and a very small staff, so what I have to balance is our involvement with these approaches, national approaches, with the work that we have to do on a day-to-day basis. And the additional work that staff within the office are being asked to do with a new approach like this, and coordinated approach like this, without maybe the necessary resources being to us, to continue with that work. This is a really important area, but we also have other areas or other like domestic violence and mortality and morbidity and those sorts of areas that also want to draw on our information, and our resources. So, it's a really delicate balancing act"*

6.2.6.3. Routinisation of processes

Data custodian participants noted that the processes of providing data and analyses to the System maybe easier as they become routine.

Participant 5: *"I suppose routinisation will make it easier. The first year there's a lot of set up, there's a lot of negotiation, there's a lot of figuring out what's useful and what's not and that's always harder so updating all of that because we're just entering into the second phase of it now, updating all of that will just naturally make things easier because people have seen it before. There will be new analyses there will be new things but compared to starting it from scratch it will be a lot easier."*

6.2.6.4. Intrinsic sensitivity of the data

Many data custodian participants indicated that one of their main challenges is in ensuring that data are not identifiable, although they acknowledged that managing the sensitivities of data is part of their job.

Participant 9: *"[...] the challenges in it are really to do with just the intrinsic sensitivity of the data and – but I don't think they are issues that are properties of the System or of the team who are implementing it."*

Participant 5: *"I could say figuring out how to confidentialise and protect individuals' identities and deal with states' concerns around that as well, states and territories' concerns around that, I could call that difficult but then that's just part of my job, this is what I do."*

6.2.6.5. Supporting a national network of data custodians

Data custodian participants mentioned that having a national network of data custodians to develop nationally consistent approaches to governance, data sharing and access would be helpful.

Participant 9: *"[...] there's a kind of – I think some of the directions that are already planned – I think it's a – it's a system that's in its early stages really, and so I think that it's not that there's new strategies that they haven't thought of that should be introduced, but I think it's yeah supporting it to continue on and get a good national network, to get those other states and territories on board to try and work through and address some of those nationally consistent approaches to governance and data sharing, data access, so I think those are all on its radar and sort of progressing those and supporting to progress those as quickly as possible."*

6.2.6.6. Communicating with custodians about the uses of data

Data custodian participants spoke about how they were not sure what their data was being used for, saying that they supply data that are used for national reporting but that the data weren't included elsewhere in the System.

Participant 13: *"See the issue is, we've been supplying all this data, quite detailed data to AIHW, but my understanding is that they're actually just using that internally for Commonwealth reporting, through to Christine Morgan [the CEO of the National Mental Health Commission and National Suicide Prevention Adviser to Prime Minister Scott Morrison] and all of that group. They're not actually including that data on the AIHW website."*

6.2.6.7. Links for System users to get further information

Data custodians suggested that having information about the source of data would be helpful for those data users who may want to contact given data custodians for more information. As an example, one participant made reference to the fact that prior to the System being developed, users of their data needed to know about their organisation to request to make data requests.

Participant 3: *"[...] they would have had to know that our surveillance unit existed... they would have had to come to us and make a request, which even though we were funded by the Department of Health, a lot of staff there didn't even know we existed [...] maybe there just needs to be links to say if you are after specific data go to the surveillance unit or go to the Coroner's Court."*

6.2.6.8. Positive experiences working with AIHW

Many data custodian participants indicated that their relationships with AIHW were positive, describing the AIHW team as being engaged and understanding their data and presenting it appropriately.

Participant 6: *"I think just the team at AIHW in the first place is really great. They're engaged, they ask questions about the data, if they're not sure about the data they come to us and look for guidance on how to interpret it. We work really closely with them with every data upload that we do, we talk to them, we make sure they've got what they need, that it makes sense. Yeah, we found it really great working with that team. So, I'm confident that they're understanding our data and presenting it appropriately."*

6.3. Group 3 key findings presented as themes

The results of the interviews with experts who have been involved in the development and/or use of known international suicide or self-harm monitoring systems are presented as themes within specific attributes outlined in the CDC Guidelines for Evaluating Public Health Surveillance Systems (22), as well as two additional categories; 'increasing the utility of systems' and 'systems through time'.

Table 6: List of themes from semi-structured interviews for Group 3.

Attribute	Theme
Simplicity	Systems are complex in nature
	Structuring systems to increase simplicity
Accessibility	Protecting privacy and confidentiality

	Getting the right data to the right people
	Building awareness of the system and actively disseminating information
Acceptability	Stakeholder buy-in and participation
Usefulness	Improving understanding of suicide and self-harm and dispelling myths
	Data for action
Additional themes outside of CDC attributes	
Increasing the utility of systems	Data collection processes, coverage, and completeness
	Importance of reciprocity
Systems through time	Establishing systems
	Developments over time
	Sustaining systems

6.3.1. Simplicity

6.3.1.1. Systems are complex in nature

Participants noted complexities within the systems they had been involved with and mostly related to dealing with challenges in capturing accurate and complete incident data. They identified the reliance on external processes, people and organisations (such as clinicians and other hospital staff, police, government organisations etc.) for data collection and reporting, making these systems inherently complex. This was particularly relevant for those systems that aim to capture incidences of self-harm presenting to emergency departments, where cases of self-harm may not always be identified or correctly recorded and coded in hospital clinical or administrative records. Participants also noted the lack of standardised international definitions of what behaviours constituted self-harm. To counter these issues, participants emphasised the importance of setting clear case definitions from the outset, training all staff responsible for data collection to follow strict case ascertainment protocols, employing staff to undergo detailed review of data entered in the systems by others, or alternatively, choosing to do all of the data collection themselves.

Participant 2 [the Oxford Monitoring System for Self-harm]: *“I guess the most challenging thing is actually identifying the non-referred cases, and we have a research clerk working on that [...] And it's quite a complicated process.”*

Participant 3 [the Irish National Self-harm Registry]: *“So I suppose that was one of the things, the main I suppose simplifying things, that we had our own team doing this. We couldn't rely on the [hospital] staff you know working with us.”*

Participants also consistently reported the need to provide ongoing technical assistance and quality control measures to ensure accurate and consistent data collection. This included providing operating manuals and training sessions to staff involved in data collection; embedding this training in induction sessions for new staff and doing regular refreshers for those already trained. Some systems also provided additional support through a dedicated virtual ‘help desk’. These quality control measures were viewed as critical to ensuring the systems consistently captured high quality and accurate data, but added complexity as they required significant resourcing by the individuals and organisation implementing the system to conduct these checks and engage, on an ongoing basis, with stakeholders at all points of data collection.

Participant 3 [the Irish National Self-harm Registry]: *“We’ve tried to be very standardised in the way that we have a clear case definition. We have trained staff who are collection data registration officers who collect the data, and they work to a standard operating procedures manual and so you know we try to keep things working the same. We do quality assurance checks where we ask one data registration officer to collect data at another hospital once they’ve got permission and they do a kind of cross over to see that they would identify the same cases as the person who usually works there and vice versa.”*

Participant 5 [the CDC National Violent Death Reporting System]: *“One of the things we do at the CDC is we provide extensive technical assistance. So as I mentioned the scientific and the information technology aspects reside on the mortality surveillance team, and [...] scientists spend a lot of time with states giving them scientific information and in terms of training the abstractors, they spend time with abstractor training at our annual meetings. [...] The system does rely on trained abstractors to enter the data and information into the system. And so we have standardised guidance in the form of a coding manual and spend a lot of time talking with the states and have monthly coding work group calls. We have a coding help desk, just to make sure that everyone’s on the same page. And so that is one of the things that we do for quality control.”*

Additional complexity was noted in circumstances where data collection spans multi-sites across a geographical area or across multiple jurisdictions. Participants identified the challenges that came with unstandardised methods of data collection across different organisations and settings, as well as the need to build and sustain relationships with those organisations to ensure their ongoing participation and buy-in to the system. Furthermore, if there were multiple organisations involved in data collection and reporting, this also added complexity.

Participant 6 [the CDC National Violent Death Reporting System]: *“It’s infrastructure that we really can’t control. There are not uniform standards with reporting by law enforcement, and there’s not one computerised system that law enforcement uses – some are using paper reports, others are using electronic reports, and the same for coroner medical examiner offices. [...] The lack of uniformity makes it more challenging. Also, with providers who may be hesitant to participate in the system, so then you don’t get that information from that particular data provider.”*

6.3.1.2. Structuring systems to increase simplicity

Elements of suicide or self-harm monitoring systems that increased their simplicity included whether they leveraged off and utilized existing digital data collection systems; integrated digital data systems for ease of data flow between levels of reporting; or included a user-friendly interface for extracting and reporting on data. Participants also linked these elements to increased timeliness and acceptability of their systems. Leveraging off existing digital data collection systems and integrating data systems, while obviously highly advantageous, was not something that could be achieved overnight; it resulted from sustained efforts, adequate resourcing and partnerships. It also required time, leadership and innovation to get up and going before the benefits flowed.

Participant 4 [the CDC Emergency Department Surveillance of Nonfatal Suicide-Related Outcomes]: *“So the data come from health departments and local jurisdictions across the US who have the data platform necessary to share data with CDC in a very timely manner [...] These data are electronic health record data so those flow to the health department and then the health department submits those data to CDC typically within 24 to 48 hours. We’re very, very timely.”*

6.3.2. Accessibility

6.3.2.1. Protecting privacy and confidentiality

All participants recognised the highly sensitive nature of suicide and self-harm data and the importance of protecting the privacy and confidentiality of every suicide death and instances of self-harm captured within their systems. All system informants commented on methods in which they achieved this including: restricting access to raw data to authorised users (usually the data custodians); de-identifying or anonymising suicide deaths or instances of self-harm within the systems; and building in systematic reporting methods and checks to minimise potential for re-identification of suicide deaths and instances of self-harm, particularly when dealing with small numbers (e.g., data from a local area or low-density geographic area). Participants also spoke to the importance of strictly adhering to the broader data governance rules developed for these systems and associated ethical approvals within specific jurisdictions. Participants acknowledged that upholding confidentiality in the system does limit the extent to which data within the system can be shared and made accessible.

Participant 4 [the CDC Emergency Department Surveillance of Nonfatal Suicide-Related Outcomes]: *“So of course the more granularity there is the more careful we are about who accesses the data and especially because of the potential for cases to be re-identified.”*

Participant 1 [the Bristol Self-harm Surveillance Register]: *“Well of course that’s always our ambition isn’t it to share stuff as much as possible, and there’s a tension isn’t there between the kind of making optimum use of data and concerns about confidentiality – particularly with a sort of smallish local dataset, you know about four or five people attending the ED [emergency department] on average a day in Bristol.”*

6.3.2.2. Getting the right data to the right people

Participants identified the importance of data in systems being accessible to those who are likely to use them. Some systems included tailored levels of access as part of their structure (e.g., restricted access database, or a service to provide tailored responses to individual requests) to accommodate different types of users and different uses of the data. Where there was restricted access to finer grained data, systems built in processes to assess potential users of the data, to ensure they have the technical understanding and skill to manipulate and interpret the data so that the data was not misrepresented. System developers have also taken on knowledge translation and knowledge brokering roles where they provide tailored data and interpretation of these data in response to requests.

Participant 4 [the CDC Emergency Department Surveillance of Nonfatal Suicide-Related Outcomes]: *“That said, while we want to make sure that the data get into the right hands of the appropriate people I think it is also really important to make sure that the people who are accessing the data on a daily basis understand the data, know how to work with the data, know how to interpret the data because it’s not something that everybody can do.”*

Participant 7 [the National Police Agency Suicide Data System]: *“Yeah I think that would help any policy makers in the local government if they can easily access the data on the spot, and if they can just basically just have online system in which they can you know pick up the municipality and then look up the data. Now of course it’s a little bit of a sensitive data, and so you have to be a little bit careful, but still I think that’s a useful thing to have.”*

Additionally, some systems with national or near national coverage have built in public facing web-based data platforms or access to data tables via a website in the effort to share data broadly from the system. If there wasn't this type of access, it was viewed as something worthwhile doing in the future.

Participant 5 [the CDC National Violent Death Reporting System]: *“Another mechanism we have for making the data available is something called wisqars, [...] it's our centralised fatal injury data platform and is NVDRS data. And so, the public can run simple data queries through that Portal.”*

Participant 7 [the National Police Agency Suicide Data System]: *“So if it's too detailed not many people can understand what's going on, but then somebody else has to aggregate the data and make it understandable, so that's a little bit of a secondary step. So again, if they have some kind of online system, they can aggregate the data at the municipality level that kind of thing, and then that would make it really easy, and then maybe some visualisation to make it easier to see. I think right now it's great but it's not super accessible.”*

However, even in the case of systems where broader access to data existed, participants suggested there was room for improvement in terms of their accessibility. This might involve improving navigation towards data sets, tailoring data access to policy makers, or making the data more user friendly through visualisation.

Participant 6 [the CDC National Violent Death Reporting System]: *“Expanding our data visualisation capabilities on the platform, and just making it like a little more user friendly, so you know if you could feel like your average journalist or person in the public who wants to know something, could very easily get the data they need and understand it.”*

6.3.2.3. Building awareness of the system and actively disseminating information

Participants spoke to the importance of system leadership and management working to actively increase the awareness of the given system and disseminating findings to relevant stakeholders involved in suicide and self-harm prevention. Participants recognised this as an essential part of their workplans. Dissemination included running specific events with stakeholders to report results and provide opportunities for feedback. Other dissemination efforts included publication of the data through reports and journal articles or assisting government representatives or regional data custodians to disseminate data to those working in suicide and self-harm prevention within their specific region.

Participant 4 [the CDC Emergency Department Surveillance of Nonfatal Suicide-Related Outcomes]: *“The whole reason that we want to collect the data is to make sure that they are used to inform prevention efforts [...] we fund the state's first to share their data with us so that we can know exactly what's going on within the states and within the counties, but then we also included a second component within that funding, that required states to develop a data dissemination plan. [This was] to ensure that the data are being disseminated to the appropriate stakeholders and the people who are doing the frontline prevention work in states and communities can really use the data to help target their prevention efforts.”*

6.3.3. Acceptability

6.3.3.1. Stakeholder buy-in and participation

Acceptability is demonstrated through the participation and interest of people on whom the system depends and their relevant organisations, as well as through participation by the community within which the system operates. Participants collecting data in emergency departments spoke to the importance of building strong

relationships and engaging with frontline clinicians and those working in service delivery and prevention efforts so that they were invested in the system and could see value in how the data being collected supported their own practice.

Participant 1 [the Bristol Self-harm Surveillance Register]: *“I think practical use, working at the sharp end of service delivery is so important with these systems. That sense of engagement with the data that they've been asked to record.”*

Systems were viewed as dependent on maintaining communication and working relationships with those collecting the data or providing access to the data. Competing demands and changing contextual factors within the hospital setting, including COVID-19 on health-care services, indirectly impacted the continuity of data collection efforts in some cases.

Participant 3 [the Irish National Self-harm Registry]: *“I think the dependence on the goodwill of people in hospitals is a frustration because, like COVID-19 has given us a good example that our data registration officer in a hospital has been a familiar face and then when they become an unfamiliar face, you know two months after a lockdown, people are saying hang on a second who are you, no you can't come in now because you have to have a swipe card for this. They say but I've been coming here for four years and you know we have the whole thing of trying to allow them access again and people just being too busy to answer letters.”*

Furthermore, the efforts required to build and sustain relationships with data custodians varied from region to region for national systems.

Participant 5 [the CDC National Violent Death Reporting System]: *“And the law enforcement agencies, there are always just so many throughout most of any states [...] that states then have to develop relationships with [...] So some states have a very complicated landscape of partnerships to work with, and others have a much easier path to collecting the data.”*

6.3.4. Usefulness

6.3.4.1. Improving understanding of suicide and self-harm and dispelling myths

All participants described ways in which their systems were being used to inform understanding of suicide and self-harm. In some cases, this was through quantifying the extent and nature of suicide or self-harm in a specified population. In others, it was by identifying trends and patterns over time in specific regions and groups. In still others, it was through dispelling myths and misconceptions around suicide and self-harm.

Participant 6 [the CDC National Violent Death Reporting System]: *“And I would just add too that what this system has done is I think it's also helped dispel some myths about suicide [...] And the vital signs that came out showed that over half, about 54%, I think it was 54% of people didn't have a known mental health condition, 54% of decedents. So, there are other things going on like job problems, relationship problems, money problems, housing issues [...] And so I think one of the things that the system has done, the usefulness, is it is helping to figure out what's going on with these people who are dying by suicide and it's helped to figure out the why, that suicide is a complex problem.”*

The use of data from these systems was reported to have also been helpful in tracking mental health impacts of COVID-19 and related lockdowns. This was particularly so for those systems that could provide timely incident data on self-harm.

Participant 4 [the CDC Emergency Department Surveillance of Nonfatal Suicide-Related Outcomes]: *“The main advantage is the timeliness of the data, getting the data in 24 to 48 hours after an emergency department visit occurred and so we can really tell especially right now these data are critical to helping us understand how the pandemic for instance is impacting non-fatal suicide related outcomes across the US. So that’s a major advantage.”*

Participants described how some systems had been used to inform understanding of risk factors. This was usually because they contained detailed data (or could be linked to other data sets), which meant that they housed information on variables like psychosocial and demographic factors, the problems people experienced preceding an incident of suicide or self-harm, or clinical problems.

Participant 5 [the CDC National Violent Death Reporting System]: *“One thing it does really, really well is the level of detail that we’re able to provide about suicide deaths and the way that it’s very possible to isolate certain characteristics of certain groups you might be particularly interested in examining unique risk factors for [...] So things like that are where you really get some very useful analytic information from NVDRS that then can be taken by stakeholders, like professional organisations, and you know the medical community interfacing with pain patients, and all kinds of other folks within and outside of public health, that can partner and prevent suicide.”*

6.3.4.2. Data for action

Participants provided examples of how their respective systems and the data flowing from them had informed policy and practice at a local, national or international level. Longer running systems and systems with strong leadership and established relationships with practitioners and government policy makers appeared to be particularly impactful over the long run.

Participant 6 [the CDC National Violent Death Reporting System]: *“And lots and lots of states use it to inform their suicide prevention efforts. I would say that the partnerships between the NVDRS programs and the suicide prevention taskforces in the state are usually quite robust, and I know [...] about a couple of states that have directly informed their suicide prevention strategies with the data from the NVDRS program in the state, which is exactly what we want to happen.”*

Participants were less able to comment on the broader use by non-government organisations and other stakeholders working in suicide and self-harm prevention, although one participant thought this might be associated with the level of accessibility of systems to these types of users.

Participant 7 [the National Police Agency Suicide Data System]: *“So the data, the national police data- definitely the government is making use of it, and tries to include, you know, use the data for suicide prevention purposes. So that’s really, I think that’s really great. But to what extent whether the organisations, suicide prevention organisations or local governments are making use of it, I’m not sure how much they are making use of it. So, I think making it accessible and then easy to understand to a lot of them is important.”*

Systems capturing relevant clinical data were able to use this information to investigate specific areas of concern or emerging patterns, such as the role of certain types of drugs in self-harm. Findings were then used to inform local prescribing patterns and even national clinical guidelines.

Participant 1 [the Bristol Self-harm Surveillance Register]: *“We also identified that some of the old-fashioned antidepressants and tricyclics were not infrequently used in overdose by people presenting to hospital for any self-harm. And so, we sought to understand better local patterns in prescribing, and communicate with GPs [general practitioners], giving them information and primary care physicians information about the frequency with which tricyclic antidepressants were taken in overdose, sometimes in quite large amounts, and just highlighting the potential hazards. So, it provided again local data which one could feedback to inform local prescribing patterns.”*

Participant 2 [the Oxford Monitoring System for Self-harm]: *“And a lot of our findings have been incorporated in guidelines on self-harm national guidelines, for example the NICE, the National Institute for Clinical Health Excellence guidelines.”*

Other systems capturing local incident data, such as the Bristol system, enabled exploration of a local suicide cluster and the connection to patterns of self-harm within the region at the time.

Participant 1 [the Bristol Self-harm Surveillance Register]: *“So a couple of years back now we had a number of student suicides, and a cluster of student suicides that’s absolutely tragic, and having access to more or less real-time suicide data allowed us to kind of see whether there were patterns emerging in terms of hospital presentations for suicide attempts as well as deaths.”*

The most recently established self-harm and suicidal behaviours surveillance system, the CDC emergency department system, has incorporated alerts to enable real-time responses to an increase in observed suicidal behaviours, though the flow on impacts of this to prevention efforts were yet to be fully understood.

Participant 4 [the CDC Emergency Department Surveillance of Nonfatal Suicide-Related Outcomes]: *“The system allows us to incorporate alerts so any time a more than expected increase in the observed suicide attempt rates or suicidal ideation for emergency department visits we can be alerted to that occurrence and again develop some response and putting in some protocols. So that’s an aspect of the program.”*

Data from some systems have also been used to evaluate management and prevention efforts, particularly in relation to those systems working to capture emergency department presentations for self-harm.

Participant 1 [the Bristol Self-harm Surveillance Register]: *“And of course it’s through that process that we, and through just seeing that quite a lot of people were slipping through the systems without being assessed, that led to greater investment in psychiatry teams, which has you know massively grown I think on intelligence we provided.”*

6.3.5. Increasing the utility of systems

6.3.5.1. Data collection processes, coverage, and completeness

Participants indicated that the utility of suicide and self-harm monitoring systems could be enhanced by simplifying and automating data collection processes, perhaps by taking advantage of routine electronic data collection systems. Expanding the coverage of data collection within or beyond a geographic region or aiming to get more complete and representative data was also seen as important to improving system utility. Linking self-harm data and suicide datasets sets to clinical services data was also seen as a way to increase system utility.

Participant 4 [the CDC Emergency Department Surveillance of Nonfatal Suicide-Related Outcomes]: *“Having more complete race and ethnicity data would be certainly helpful for us. We constantly get asked the question by our Department of Veterans Affairs and our substance abuse and mental health services if there’s a way to capture veteran status so whether have people have ever served in the military because we know that in the US that population is at high risk for suicide, so being able to collect some information like that would certainly be helpful.”*

Participant 1 [the Bristol Self-harm Surveillance Register]: *“So there’s an absence of you know connections or whether they present to hospital and we collect some data and unless they represent to hospital we really don’t know how they’ve got on and whether they’ve engaged with mental health services at all or whether it’s worked out for them.”*

6.3.5.2. Importance of reciprocity

Participants raised the importance of systems being integrated with clinical practice and services so that the data flowing from these systems could inform the day-to-day activities of those working in suicide and self-harm prevention and management. The concept of reciprocity, the practice of exchanging things with others for mutual benefit, was considered central to systems elevating their utility and should be prioritised as part of newly established systems.

Participant 1 [the Bristol Self-harm Surveillance Register]: *“I think as a community we need to make it quite reciprocal. You know there are national surveillance advantages, but if you’re going to get good quality data it has to be shared, and there are ways that the collection of data in real-time can feed into practice [...] those are the things I would work on in terms of developing your system.”*

Participant 5 [the CDC National Violent Death Reporting System]: *“I think just you know even more dialogue and partnership between you know that kind of goes seamlessly from data collection to the right partners receiving the data and wanting to act on the data. And then kind of feeding that through that system to say okay and here’s what happened and here’s how it turned out and let’s evaluate it. I think we would love to see that process kind of be more uniformly smooth, and for us to really you know always have a great picture of how the data is being used.”*

6.3.6. Systems through time

6.3.6.1. Establishing systems

Participants reflected on different stages of the implementation of their systems. Establishment of systems, particularly those related to collection of self-harm data in emergency departments appeared to result from the interest and momentum of pioneering researchers working in self-harm and suicide prevention who recognised the need to develop the system and possible ways to go about doing it.

Participant 1 [the Bristol Self-harm Surveillance Register]: *“We developed the system following discussions with fantastic colleagues in Oxford and in Manchester [...] so we kind of built on their levels of knowledge.”*

6.3.6.2. Developments over time

Participants noted that systems evolved iteratively over time, with improvements relating to increasing the coverage of data collection, improving data quality, completeness and timeliness, instituting changes relating to data governance or clinical practice, or expanding the type of data collected and the uses of data from the system for service planning and policy. Sometimes these developments presented new challenges.

Participant 4 [the CDC Emergency Department Surveillance of Nonfatal Suicide-Related Outcomes]: *“This system, the national syndromic surveillance program, has grown exponentially over the last couple of years [...] We’ve reached a point where about 70% of US emergency departments are contributing data to the system and so that’s wonderful, obviously the more coverage the better, however it makes understanding and examining trends over time a little bit difficult. It’s difficult because we’re having to factor in that new hospitals are constantly coming on board and so that’s going to make our numbers look greater and greater. The way that we account for that is by looking at the percentage of all ED [emergency department] visits that are suicide related as opposed to the number of visits that are suicide related and that can get difficult when you experience times when the overall number of ED visits changes for some reason. We’ve seen that just recently during the pandemic because people were specifically told to try to avoid emergency departments and so for that reason, we’ve seen a little bit of unanticipated activity and really difficult to interpret outcomes related to suicide related ED visits.”*

Developments that have occurred over time were not necessarily envisaged when the system was first created.

Participant 2 [the Oxford Monitoring System for Self-harm]: *“And then as time went on, we realised that the data could be used for a wide range of, an increasing range of purposes, some of which I couldn’t have imagined. For example, we’ve used them to look at the relative toxicity of drugs used for overdose by comparing presentations with non-fatal poisoning with specific drugs, to national data on deaths involving those drugs, and have published a few papers on that. So a wide range of studies [...] I would say we’ve done a heck of a lot more than I ever envisaged at the beginning of all this, I would never have imagined some of the things that we’ve been able to do.”*

6.3.6.3. Sustaining systems

Participants identified sustained and appropriate levels of funding as inextricably linked with ongoing performance, and further development and use of the systems. Funding shortfalls directly impacted the human and capital resources available to maintain, update and maximise the utility of systems. On the flip side, adequate funding was identified as key to increasing the coverage of systems.

Participant 1 [the Bristol Self-harm Surveillance Register]: *“the main difficulty we had was that we received funding on an annual basis, and so you got good staff trained up and then they would inevitably get anxious towards the end of their contracts at the end of the year. And so, we lost people for that reason, and so the continuity wasn’t always fantastic [...] So, the disadvantage was as a result of it being underfunded, you know these sorts of things if they’re going to be done properly need really good levels of funding.”*

Participant 2 [the Oxford Monitoring System for Self-harm]: *“I guess one of the main things would be to have more funding, a) to support the data collection, but in some ways more importantly to b) allow us to do more with the data. So, you know doing the analytical work for a lot of the studies we do is pretty complex, and time consuming and we don’t have you know a lot in the way of research staff working on those data. So, the other thing that would improve things is if we could get our data much more up to date so we can provide more contemporary information, particularly related to local suicide and self-harm prevention policy and so on.”*

Participant 6 [the CDC National Violent Death Reporting System]: *“I have to say that I work with an extraordinary group of people on NVDRS, and as we have continued to expand, I mean it’s just been great having the resources to now reach all 50 states, DC and Puerto Rico is amazing.”*

6.3.7. Summary of Group 3 interviews

Participant reflections of suicide and self-harm surveillance systems overall highlighted that these systems have played, and continue to play, an important role in supporting suicide and self-harm prevention research, policy and practice in their respective regions and countries. These systems have required intensive efforts to be established but also ongoing technical assistance and quality control measures to ensure accurate and consistent data collection over time. They have relied on strong working relationships with those collecting the data or providing access to the data. Participants stressed that newly established systems should prioritise greater access and integration with clinical practice and services so that the data flowing from these systems may inform the day-to-day activities of those working in suicide and self-harm prevention and management. Sustained and appropriate levels of funding was viewed as a key factor for improving the performance and utility of these systems.

7. Case studies

7.1. Our approach

Two case studies were completed to evaluate the usefulness of the System. Qualitative case studies enable exploration of phenomena within their natural environments using a range of data sources and collection methods (36). Usefulness refers to whether the System can contribute to the prevention and management of suicide and self-harm including an improvement in System users' understanding of the public health implications of suicide and self-harm (22). The case studies were largely informed by the preliminary findings of the semi-structured interviews in addition to the other components of the evaluation that were undertaken. The first case study was centred around an organisation that was known to have interacted with the Published Site (i.e., Western NSW PHN). The second case study was centred around other specialised contributors to, and users of, the Dashboard; a process and product utilising the System for monitoring and reporting of population mental health impacts during COVID-19, including reporting to the National Cabinet and Prime Minister's Office (i.e., Australian Department of Health and other government officials). Participants in each of the case studies were asked questions as part of uniquely developed interview guides that were designed to understand how stakeholders used the System in addition to understanding how the System could be improved to better cater to the needs of users in the future.

In collaboration with the AIHW, we used purposive sampling to identify the participating organisations and individuals as cases. We recruited participants via email. The email invitation included information about the National Suicide and Self-harm Monitoring System, information about the evaluation, and a link to the online Participant Information Sheet and Consent Form. Participants who indicated they would like to participate in an interview and who completed their consent forms, were contacted by our team to organise their interview. There were no incentives for participants of the case studies other than the knowledge that they were contributing to the development and implementation of the System that will inform suicide prevention in Australia.

The question guides were informed by the CDC framework to evaluate public health surveillance systems in combination with the results from the semi-structured individual interviews that had already been undertaken as part of this evaluation. The interviews were audio recorded, transcribed verbatim and transcripts were imported into NVivo version 12 for analysis. A thematic analysis was conducted using both an inductive and deductive approach. Thematic analysis identifies, organises and interprets patterns in qualitative data (37). Within each set of results (see 7.2.6 and 7.3.3) individual participants and quotations have been represented by a number (i.e., participant 1, participant 2 etc.)

7.1.1. Case Study 1: the Western New South Wales Primary Health Network

One semi-structured group interview was conducted over Zoom with key employees who work in suicide and self-harm prevention at the Western New South Wales PHN. These participants were specifically identified so that we could understand how the Western New South Wales PHN used the System to inform their organisation's suicide and self-harm prevention efforts. In total, three people were invited to attend the group interview and all three attended.

The semi-structured group interview was conducted on 14 April 2021 and lasted approximately 60 minutes and was conducted via Zoom. The interview guide was developed to measure the usefulness of the System in addition to any potential improvements that could be made to the System.

7.1.2. Case Study 2: the Dashboard

Semi-structured interviews were conducted with employees of the Australian Government Department of Health and other state and territory government officials who are contributors to, and or users of, the Dashboard. These participants were specifically identified so that we could understand how the Dashboard had been used by various stakeholders within state and federal government to inform the government's understanding and response to mental health, suicide and self-harm.

In total, nine people were invited to participate in the semi-structured interviews and all nine participated. The semi-structured interviews lasted approximately 30 minutes and were conducted via Zoom. Five of the interviews were individual, two interviews had two participants with one individual, and two were with two individuals each. The interviews were conducted between 11 August and 21 September 2021. The interview guide was developed to measure the usefulness of the Dashboard and to identify any potential improvements that could be made to the Dashboard.

7.2. Case Study 1: Western NSW PHN's use of the Published Site

7.2.1. Primary Health Networks

Primary Health Networks are funded by the Department of Health to commission a range of services designed to meet local health needs. There are 31 PHNs across Australia and they are expected to improve health care (particularly for individuals with higher risks or poorer outcomes), prioritise health care spending for increased effectiveness and efficiency, and improve coordination between health care services within their region.

A key requirement for PHNs to achieve these goals is their ability to assess the health needs of their community. Needs assessments provide information about the health needs of the community, existing services, and the new services required to meet any gaps. Assessing where to best locate staff and services is also part of the needs assessment process and contributes to resource allocation decision making aimed at improving efficiency and cost-effectiveness of health care in the region. The Australian Government has a defined process for PHNs to use to conduct these needs assessments and this process includes the requirement that they analyse relevant local and national health data (38). PHNs are advised to use the Australian Statistical Geography Standard Statistical Area 3 level for analysis within the PHN and to use smaller geographical divisions such as Local Government Areas as needed and where available. PHNs are also advised to focus in on the health needs of population sub-groups who may experience unique or disproportionate health concerns such as young people or Indigenous people.

7.2.2. The region

At the time this case study was conducted, Western NSW PHN was geographically the largest PHN in NSW covering 53.5% of the area of that state (see Figure 6) (39). It comprised both the Far West and Western NSW Local Health Districts and included more than 309,900 people. More than 400 general practitioners operating from more than 100 practices were supported by Western NSW PHN. Approximately 10.5% of people in Western NSW PHN identified as Indigenous (40). Compared with all of NSW, the Western NSW PHN had a higher proportion of people under 20 and over 64 years of age (19.4% under 20 years compared with 16.7% in NSW, 26.6% over 64 years compared with 24.2% in NSW) (41). More than a third of Local Government Areas within the Western NSW PHN were classified as remote or very remote, and more than a third were classified as the most socio-economically disadvantaged nationally (40). In comparison to the wider

Australian population, the Western NSW PHN region had the second highest single parent family rates, higher rates of low education levels, higher rates of young people receiving unemployment benefits, and a higher proportion of people living with profound or severe disability (40).

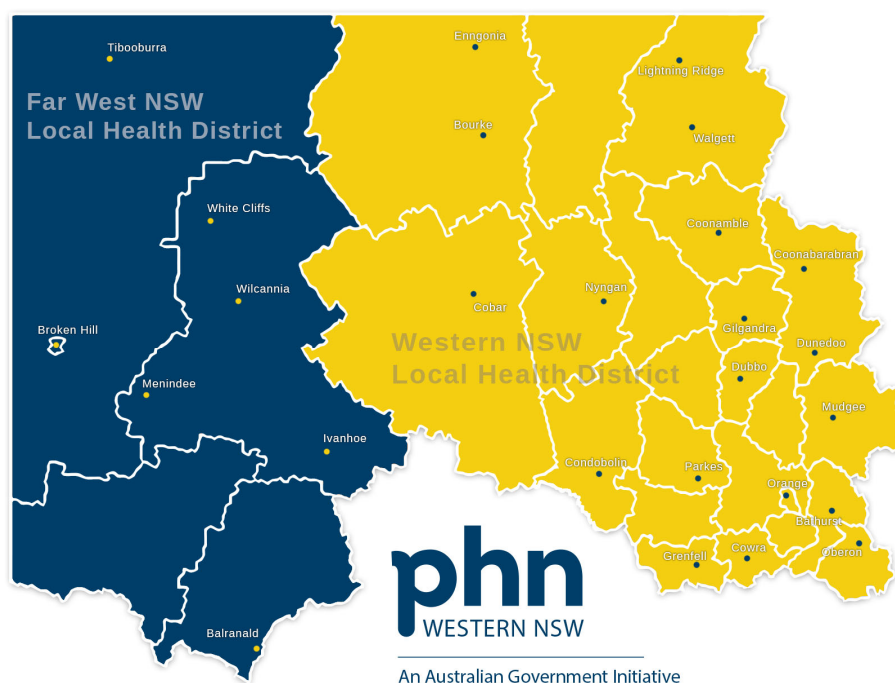


Figure 6: Map of the Western New South Wales Primary Health Network, including the Far West NSW and Western NSW Local Health Districts (39).

7.2.3. Suicide prevention at Western NSW PHN

Mental health has been a key priority area identified by the Australian Government for PHNs to focus their efforts on and has been taken up by the Western NSW PHN (42, 43). A ‘stepped care’ model has been used to plan mental health and suicide prevention services to most effectively and efficiently meet individual and population needs (44). A challenge that the Western NSW PHN has identified in implementing the stepped care model is determining the most effective and efficient distribution of the workforce across the region (44).

As of October 2020, the Western NSW PHN had commissioned 14 programs to improve mental health, including four which targeted suicide prevention (45). Some of these programs were provided to the whole region while others were available only in specific locations. Several were designed for specific sub-groups, including young people, Indigenous people, and people with severe or complex mental health problems. All of the suicide prevention programs aligned with the Black Dog Institute ‘LifeSpan’ approach, using evidence-based strategies to improve access to and efficacy of health care by training health and other service providers as well as community members in suicide prevention (43, 46).

The suicide prevention efforts for Indigenous people in Western NSW PHN have been supported by Wesley LifeForce Indigenous Suicide Prevention (43, 47). This program has worked to increase awareness and empower local communities to support people most at risk of suicide. Western NSW PHN were also involved

in several trials and other intervention development activities to address suicide and improve needs assessments. These included the National Suicide Prevention Trial (48), community consultation and engagement activities (49), and the Black Dog Institute and SAS Institute® collaborative suicide prevention data workshops (see Section 4.2).

7.2.4. Data from the Published Site

The Published Site contains information about suicide deaths and intentional self-harm hospitalisations in Western NSW PHN. At the time this case study was conducted, the Published Site showed that in the recent years preceding the case study, the age-standardised suicide rate in Western NSW PHN was higher than the rate for all of Australia. Preliminary data for 2018 and 2019 respectively showed 16.6 and 16.2 suicide deaths per 100,000 people in Western NSW PHN, compared with 12.4 and 12.9 suicide deaths per 100,000 people in the wider Australian population. The Published Site also showed that the age-standardised rate of intentional self-harm hospitalisations in 2019–20 in Western NSW PHN were highest in females aged 0–24 at 214.6 per 100,000. Males aged 25–44 had the next highest intentional self-harm hospitalization rate in the region at 161.9 per 100,000. Western NSW PHN had the highest rate for both age and sex groupings within NSW.

Information about suicide and intentional self-harm hospitalisations was available on the Published Site for the eight SA3 geographical areas that made up Western NSW PHN. The number of suicide deaths which occurred over the five-year period 2015–19 was reported for each SA3 as shown in Table 6. The age-standardised rate was also reported where there were at least 20 total deaths and the population within each age group was at least 30. The number and crude rate of intentional self-harm hospitalisations 2018–19 was presented on the Published Site at the SA3 level for each sex and for all persons by three age groups as shown in Table 7. Crude rates were suppressed where there were less than 10 intentional self-harm hospitalisations in an area, or the population was less than 100.

All of the information presented on the Published Site and described above was also available in Excel spreadsheets to be downloaded from the site. Additionally, other time periods, and suicide deaths data by SA4 and sex were available to download. The eight SA3s within the Western NSW PHN were divided over three SA4s. One of the SA4s included in the region comprised data from one SA3 from the Western NSW PHN and two from an adjacent PHN, which may mean that data at the SA4 level was not as useful for Western PHN planning for that geographical area within the region.

Table 7: Suicides in Western NSW PHN by Statistical Area 3, 2015–19.

Statistical Area 3	Number of suicide deaths	Age-standardised rate per 100,000
Bathurst	31	12.2
Lachlan Valley	44	17.1
Lithgow-Mudgee	37	16.2
Orange	37	13.3
Bourke-Cobar-Coonamble	12	n.p.
Broken Hill and Far West	22	19.4
Dubbo	51	14.2

Lower Murray	13	n.p.
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*Data from the National Suicide and Self-harm Monitoring System's Published Site. "n.p." represents unpublished data.

Table 8: Intentional self-harm hospitalisations in Western NSW PHN by Statistical Area 3, 2018-19.

Statistical Area 3	Females		Males		0–24 years		25–44 years		45+ years	
	#	rate / 100,000	#	rate / 100,000	#	rate / 100,000	#	rate / 100,000	#	rate / 100,000
Bathurst	23	95.5	15	61.3	20	119.8	11	94	7	n.p.
Lachlan Valley	22	78.1	10	35.7	13	73.5	8	n.p.	11	40.7
Lithgow-Mudgee	19	80.1	11	45.2	10	70.0	10	94	10	43.2
Orange	53	174.0	31	105.6	41	202.4	25	169.1	18	72.6
Bourke-Cobar-Coonamble	8	67.5	9	n.p.	7	n.p.	n.p.	n.p.	n.p.	n.p.
Broken Hill and Far West	25	244.7	20	199.7	12	210.2	21	445.1	12	122.4
Dubbo	31	84.7	28	77.4	23	95.8	21	119	15	48.2
Lower Murray	n.p.	n.p.	n.p.	n.p.	6	n.p.	n.p.	n.p.	n.p.	n.p.

*Data from the National Suicide and Self-harm Monitoring System's Published Site. "n.p." represents unpublished data.

7.2.5. Participant demographics for Case Study 1

There were three participants from the Western NSW PHN who completed a group semi-structured interview as part of this case study. Participants in this case study had significant experience in suicide prevention. Some worked with individuals who were at risk of suicide or experiencing suicidal crisis. Others were responsible for planning and implementing community-level suicide prevention efforts and even national resource development. The participants also had substantial epidemiological experience, including with population interventions and the use of suicide related data from difference sources. The findings from the group interview for Case Study 1 are presented as four themes.

7.2.6. Case Study 1 key findings presented as themes

The results of the group interview are presented as themes focused on the attribute of usefulness. Usefulness refers to whether the System can contribute to the prevention and management of suicide and self-harm including an improvement in System users' understanding of the public health implications of suicide and self-harm (22). The themes include: regular data use within the PHN; use of the Published Site; other sources of information; and unmet needs and data challenges. Together these results convey the overarching needs of the PHN with regards to data, the ways in which the Published Site has meet those needs, other data sources required to meet any remaining needs and the needs that are yet to be met.

7.2.6.1. Regular data use within the PHN

To understand the needs for which the System may be used, participants were asked about the purposes for which data were collected. Participants described the primary purpose of data collection and analysis at Western NSW PHN was to understand the health needs within the region. This informed questions of where services are most needed and by whom, and it also allowed more efficient and effective planning and allocation of available resources to ensure services were funded where they were most needed.

Participant 1: *“So understanding the needs of the population obviously helps to plan how best to address those needs, what services might be needed, where those services are needed, where there are gaps. And I guess for any health organisation there's limited funds, and it's weighing up, understanding how best the needs can be met, and where those services are probably needed more, compared to other regions.”*

Participants provided examples of challenges in deciding where to establish services within the large region.

Participant 2: *“Now one recent example is we, I mean like our region was 330,000 square kilometres, so we're talking quite large distances. And we received funding to establish one Way Back Support Service, which is a support service for people after attempted suicide. So, you've got this impossible decision, where is the best place to locate this service.”*

Participants described situations where data were used to select a service and resource placement in the areas of the region where the need was greatest.

Participant 2: *“Our PHN was one of 13 PHNs across Australia selected to be involved in the National Suicide Prevention Trial. So again, we've got this vast area and it was funding of \$1 million per year, initially for two years but then it's gone on for four years. And there's no way the million dollars is going to spread across our region. So then obviously we're having to select sites where the initiatives should be based. So went straight again to the data to look at rates of suicide and self-harm to select and it wasn't solely the data, the data was giving good signposts, but then that sort of supplemented with local knowledge about you know the service sector, the ranges of sectors, the range of services that were available. How many vacancies exist perhaps in local health district positions? So you can get a bit of a sense of which communities have got higher rates, but also doing it tough for other reasons, or because they've also got a higher prevalence of risk factors or risk populations.”*

In addition to needing data to understand health needs, participants noted that timely data and alerts are needed to respond to concerns about immediate spikes in suicide and self-harm and to put supports in place.

Participant 1: *“Ideally, we should be able to quickly mobilise support for community where a death has occurred, you know there's specialised grief and bereavement support services that can be connected into the community. But obviously we can't get on the phone and start sort of putting those wheels in motion unless we've got good quick reliable alerts that a death has occurred.”*

Participants talked about the fact that they receive queries from journalists, politicians, and community members about rumoured increases in suicide among specific age groups or in specific areas. Adequate and timely data is usually not available to check on this information. Instead, staff use informal networks to find out what service providers and others may know.

Participant 2: *“There was an occasion about 12 months ago where I got contacted because we worked with the suicide prevention unit in the Department of Health, and they [said] we’ve seen an article in one of your local newspapers, where a Member of Parliament has quoted, has said that you know X number of deaths had occurred amongst young people, because of COVID-19. She said can you find out, is there any truth in that. [...] So, I’d just sort of get on the phone to my networks of service providers, youth service providers and say look have you got any idea where this is coming from to try and fact check. Because short of [...] informal relationships with police, there is no other way that we could fact check deaths.”*

Participants described the way they used data to fact-check and ensure media and other reporting within the region was accurate and adhered to *Mindframe* guidelines.

Participant 3: *“We’ve utilised Mindframe support a number of times to get stories taken down or rejigged, because of claims that have been made and the way that they’ve done things [...] so we have a pretty good comms team who are on the ball [...] we have one state politician who I think our comms team has approached on multiple occasions to offer him some training about reporting or talking about suicide in the media.”*

Participants described using local suicide and self-harm data to compare with state and national data to gauge how the Western NSW PHN region is faring.

Participant 1: *“I’ve been updating a PHN regional profile, so we like to see how the health outcomes, at a regional level compared to other PHNs.”*

7.2.6.2. Use of the Published Site

Announcements through social media channels alerted participants of the Western NSW PHN to the new Published Site. Participants had used data on the Published Site to update the regional profile of the PHN and to compare the region with other PHNs. Participants found the Published Site data offered a broad range of information and was useful for providing context at educational events.

Participant 3: *“I have looked at this data and used the broader statistics just to give the context, and so it’s really helpful for those purposes just I guess to lay the groundwork and set the scene.”*

Participants noted that the nationally consistent data had been helpful to verify local findings from other sources and to cross-check for areas of concern. The psychosocial data had also been helpful by reminding service planners of risk factors associated with suicide.

Participant 2: *“I think that is really helpful to again remind us of what are the higher risk factors. So that’s sort of good at a high-level thinking and planning purposes.”*

Participants felt that additional data on risk factors would be helpful as well as more detailed data breakdowns by, for example, Local Government Area level, suicide method and age. The data available on the Published Site was identified as being good for high-level planning and analysis but requiring supplementation from other sources to make decisions within the PHN, such as what resources to commission and where to place them.

Participant 3: *“So, in the system, you know you’ve got zero to 14 [years of age] and then the next bracket. Well, there’s actually you know one year, 17 or 18, was the high, was throwing out all of the other numbers. So, if we were to do an intervention and we were looking at you know, 15-to-16-year old’s because there’s when you think you know, life’s changing and all that, but you might need to actually instead drive more effort towards this one particular gap in that area, rather than taking a blanket approach, [...] having more data or more, something that you can zoom in on would be helpful [...] in terms of interventions, yeah we probably need just a bit more.”*

7.2.6.3. Other sources of information

In order to meet the data needs of the PHN, participants described the need to source data from a wide range of sources. These included data from the Australian Bureau of Statistics, Bureau of Crime Statistics and Research, Population Health Information Development Unit, NSW Health, local Police, local health districts, telephone surveys, and PHN Exchange. Participants noted that the Population Health Information Development Unit and the NSW Government’s HealthStats NSW have often been used to source data, particularly Local Government Area level data for self-harm hospitalisations.

Participant 1: *“HealthStats is a publicly facing data resource that I tend to use a lot, because I guess thinking about how the AIHW report a lot of their data at that subregional level, SA4s and SA3s, whereas we tend to work in LGA boundaries because for the most part they’re better defined, whereas SA3s and SA4s cut across more than one boundary usually, so we like to group. And it gives you a better focus. So LGA data for some of the indicators, particularly around self-harm, hospitalisations are available at a local government area level on HealthStats.”*

Participants described trust and relationship building with local police commanders. Those relationships allowed the PHN staff to obtain important and timely data. The police data had been important to participants for understanding mental health and suicide related needs in the region police attended and were first responders to approximately 90% of emergency calls about mental health in some areas. Additionally, some areas required individuals to have a police escort to access emergency department services.

Participant 2: *“It’s the nature of the beast that as you get more remote you know police do become the de facto health service delivery system, because the communities, particularly the isolated Aboriginal communities, have very few other options for after-hours.”*

Participants reported that police data were close to real-time, particularly for deaths, and the data were not available elsewhere. Workshops held by the PHN with police included training to deal with mental health and suicide related call outs. Those workshops facilitated discussions where police identified potential issues with prescription drugs and poisoning deaths which allowed the PHN to work with doctors towards solutions.

Participant 3: *“We did a bit of training with them, but also used it as a workshop to sort of get some ideas about what’s actually going on.”*

7.2.6.4. Unmet needs and data challenges

One of the most significant needs raised by the participants was the need for more detailed data within their region. Decisions about which services to commission are made at the LGA level as they're better defined and provide better focus.

Participant 2: *"more detail of course would be my primary hope and LGA based data, because presently the information that's available is great for just high-level planning and analysis, but for decision making about what to commission and in what location, you'd have to go to other sources to supplement."*

Participants observed significant differences in the health needs of areas and sub-groups of the population due to the heterogeneity of the region.

Participant 1: *"We have a lot of other smaller towns that have less services. And the issues we find are that the health of people living in those more rural and remote regions are worse and not just with mental health, with many other chronic diseases [...] So obviously living away from those service centres affects the health of the population, so that's why we need to understand the health of not just the whole of the population, but the smaller populations. And then the vulnerable groups within those populations, so Aboriginal people, older people, younger people, and they tend to use services more."*

Although participants stressed the importance of having access to more detailed data, they also acknowledged the associated challenges. The region comprised 27 Local Government Areas, some with very small populations and even smaller sub-groups, such as Indigenous people and young people.

Participant 1: *"Because for us, for our PHN we've got a low population density, so we've got you know about four percent of the state population spread out over more than half of the [area]. So straight away that means you've got low numbers which affects the confidence, the reasons that the data is so tied down is because there's an agreement to protect the confidentiality of the people whose data it belongs to, so that presents a big problem in our region. And that's why we have the struggles with trying to get the data, so it's a balance. You know we need that data to be able to understand the needs, and to plan services, but we understand at the same time we've got low numbers and it makes it difficult."*

Compared with all of NSW, Western NSW PHN had a higher Indigenous population and some LGAs where a very high proportion of the population identified as Indigenous. In this context, participants discussed the priority of identifying needs of Indigenous people in the region.

Participant 1: *"Top of the wish list is quality Aboriginal data at a sub-regional level, because the problems we've encountered in trying to access Aboriginal data, because a lot of it is you know the AMSs have a lot of this data and they report it to a national database, and that's all they have to do. And for us to be able to have access to that data we would have to individual approach all the [different organisations]. Now we don't have the resources, staff wise or funding to be able to do that. So, looking nationally what would be fantastic is if there could be a national ethics approval process that allowed Aboriginal data to be reported on a site like that. And I understand you know there would be a need to protect the identities of people, but even if we could have more – there is some data by aboriginality at a PHN level, but it would be fantastic to have a greater range of indicators. Because for us they're a very important vulnerable population that we need to be doing a lot more work with."*

As previously indicated, participants described police as being the first and primary responders for mental health and suicide needs in many remote contexts. They also noted, however, that they have struggled to obtain ambulance and police data.

Participant 1: *“An issue that [we] have encountered in our journey with understanding suicide, is around ambulance and police data. So trying to get that has been a challenge. And I see now that you're probably all aware of it, but I wasn't aware that there's now work being done on getting national ambulance surveillance systems, so yeah if that comes together that will be incredibly helpful. But again, we need to be, if that data can be available, that can be drilled down.”*

Participants identified the merits of an accessible one-stop-shop with all relevant data needs in one place.

Participant 1: *“So often people who need to use the data may not have an intimate understanding of data, so you need something that people in all, at all levels of health service planning and delivery and needs assessment, can understand at a glance. So that's the challenge I think for everyone, is to be able to have a data source that can be used to plan but can also be used to monitor and evaluate. So having something that trend data as well is really critical to be able to evaluate if strategies are effective.”*

7.3. Case Study 2: contributors to and users of the Dashboard

7.3.1. Background

The Dashboard is a collaboration between the AIHW Mental Health Unit and the Australian Department of Health Mental Health Division to produce, analyse and report mental health related data since April 2020. Data is derived from several sources including the Medicare Benefits Schedule, the Pharmaceutical Benefits Scheme, Government funded services (headspace, Beyond Blue, Kids Help Line, Lifeline), state mental health service data and additional research findings and other related data. The outputs of this data collation are national and jurisdictional versions of the Dashboard. The Dashboard was developed because of the Australian Government's identified need to monitor the mental health of Australians during the COVID-19 pandemic. The purpose of the Dashboard is to ensure that state, territory, and federal government departments have up to date information on issues related to mental health, suicide, and self-harm in Australia. Departments who have received the dashboard includes: National Cabinet and Prime Minister's Office, the Australian Government Minister for Health, the National Suicide Prevention Advisor, and state, and territory health departments. The Dashboard is presented as an A3 sized PDF with Commonwealth, NSW, ACT and Victorian specific versions.

7.3.2. Participant demographics for Case Study 2

There were nine participants who completed semi-structured interviews as part of this case study. Five of the interviews were conducted individual and two involved two participants. All participants had contributed to, or been a user of, the Dashboard and worked in Australian Government or state or territory government departments at the time. All participants had significant experience in their professional roles and in working with mental health data.

7.3.3. Case Study 2 key findings presented as themes

The results of the interviews are presented as themes focused on the attribute of usefulness. Usefulness refers to whether the Dashboard can contribute to the prevention and management of suicide and self-harm including an improvement in System users' understanding of the public health implications of suicide and self-

harm (22). The themes include: content and purpose of Dashboard; access to the Dashboard; policy outcomes of the Dashboard; improvements to the Dashboard (online Dashboard platform); improvements to the dashboard (continuation and increase in data sharing); and added value and continuation of the Dashboard.

7.3.3.1. Content and purpose of the Dashboard

Participants were asked questions about what types of data were included in the Dashboard and what the purpose of the Dashboard was.

Participants described the types of data including Medicare, headspace, crisis lines, Head to Health and jurisdictional specific data for New South Wales, Victoria, and Queensland.

Participant 5: "So well the types of information obviously are data from Medicare, headspace, a lot of the digital support services, the main crisis lines, Head to Health activity and then more recently there's been a supplementary placemat [Dashboard] for jurisdictions that includes New South Wales, Victorian and now Queensland data about their specialised mental health services, hospitals and ED [emergency department] admissions and it just aggregates some of that data down to the state level as well and then as part of that product suite there's also a summary of the latest suicide information coming out of the registers and we supply daily Lifeline data to PM&C [...] it gets included in an economic dashboard that they prepare as well for the PM."

Participants described the Dashboard as providing flexible outputs with both an interactive option and static PDF that can easily be printed.

Participant 1: "It's both, the product we produce for the Prime Minister is a PDF, he likes something he can print out. I mean we've given the office, so our client is effectively the Prime Minister but also his office, we've given the office access to interactive, the interactivity on it, but the Prime Minister still likes a nice printed A3, so we do that up for him."

One participant described the purpose of the Dashboard being 'a real-time finger on the pulse' and made specific reference to 'what was happening on the ground' during the COVID-19 pandemic in Australia.

Participant 8: "it was as real-time, finger on the pulse data in terms of the impact on Australians and the pandemic, but in particular the restrictions or responses from government in relation to what was happening at the height of COVID-19 and in an ongoing basis, but that was, it was to feed into government decision makers and understanding of what was happening on the ground."

Another participant described the main purpose of the Dashboard being to support briefings with the Prime Minister.

Participant 5: "the main purpose is to support briefings with the Prime Minister that happen every fortnight on mental health and kind of social policy. When we initiated the placemat [Dashboard] that was weekly, so it was sort of part of informing that initial response it started I think in about April last year, so it's really been focused on helping the Prime Minister understand how the COVID situation has been impacting the mental health of Australians and keeping an eye on the suicide rates and suicide risk in the population."

Another participant not directly involved with briefing the Prime Minister noted that the Dashboard was a helpful first step for highlighting the value in the data's timeliness.

Participant 2: *“it’s brought together a lot of various data sources together into a cohesive interactive platform which has been a really useful first step tool and it is really sort of driving that more, that currency that constantly updated data source which is very valuable.”*

Another participant discussed the access to new data that they did not previously have access to.

Participant 3: *“The fortnightly meeting has allowed us to bring together that data and we haven’t had access to, for example, Medicare Benefits Schedule data before and we’ve got it by statistical area three and we’ve got it by age group splits.”*

7.3.3.2. Access to the Dashboard

Participants were asked about who currently receives the Dashboard and whether other government departments or non-government organisations should have access to it. Participants discussed who the different state and territory versions of the Dashboard are delivered to and the current necessity to keep the data within government.

Participants described how they generated and delivered specific state, territory and national versions of the Dashboard and talked these through with premiers and department heads, highlighting that this data sharing has led to collaborations where departments are ‘on the same page’.

Participant 1: *“State Premiers receive a certain cut of it through the national cabinet process, and what we often do is we’ll do up a product for the State Premiers and then we’ll talk their departments through it. Sometimes we will even talk the Premiers through it. So, that’s actually been a really useful component because a lot of Premiers are able to go ‘oh ok this is information that I haven’t seen from my own bureaucracy’. [...] This has actually been a really interesting experiment of AIHW being on the same page as Health, and we find that often when you talk to state Departments of Health, they’re not joined up with the state departments of Premiers and Cabinets, and so it’s often kind of a joining exercise, and I know the states actually very much appreciate receiving the data as well.”*

Participants also discussed challenges with collaboration during COVID-19 and department restructures and needing to connect with others within their department who would be involved with generating policy responses.

Participant 3: *“[...] of the things that’s important is sort of linking into policy people. So, I know there are people in the Department that are really looking at the sort of under 18s issue, but I don’t necessarily have a direct path to them so, I guess that’s something that is also really important. It can be hard to sort of sometimes make those connections and at the moment you know we’re all working at home and, in the past I used to just you know hop in the stairs or take the lift and just turn up at someone’s desk and, you know, often that was actually really helpful. Whereas, you know some of that is more difficult now and we’ve had a lot of change and a restructure so that linking in I guess to the sort of policy responses that are suggested by the data is probably that could be strengthened.”*

Participants discussed who should have access to the state and federal Dashboards. They highlighted that there are reasons it is sometimes difficult to share the data outside of government, citing the potential for misinterpretation or catastrophizing representation.

Participant 3: *“I’m sort of in favour of making data available to people and particularly to researchers but you sometimes feel with some of this stuff that people you know there’s a risk of sort of increasing the level of distress that families and young people may already be feeling so I don’t know. It’s definitely health*

information, I think we do share some things with Education and obviously they've got a big part in dealing with young people. The agreement with the Commonwealth is that it's to be kept in government so we can't you know give it to people who are outside government."

Participant 4: *"And again, there is a value, and this is why states and territories have been willing to share, there is a value in saying we will keep this close, we will not let it get out to places where it could be misinterpreted or presented in an overly dramatized catastrophizing way."*

7.3.3.3. Policy outcomes of the Dashboard

Participants were asked about how they engage with the Dashboard, whether they thought the information in the Dashboard was useful, and whether they could think of specific actions that had resulted from the Dashboard.

Participants described the Dashboard as a useful reference point for responding to issues that are immediate, as well as a starting point for going back to the AIHW System to inform policy work that they are doing.

Participant 2: *"I mean it is a useful reference document for me. I suppose in terms of sort of the current issues, I mean it is useful background to, I guess, respond to the immediate issues that are presenting themselves. We also have gone back to the broader system as a whole the AIHW broader system in reference and in sourcing information and data about some of the policy work that we might be doing."*

Participants described the data in the Dashboard as being useful for informing social policy and noted that the data help policy makers see issues as not just social issues or economic issues but as 'fused' issues.

Participant 1: *"To be honest, if you'd asked me four or five years ago whether social policy had such a massive impact on things like economic growth, I would've been like, I don't think it does, but I think that that has genuinely changed, and that's where it's really useful, stuff like the AIHW data is useful in that, even in the policy formation process, because we're not just seeing something as just an economic problem, or just a social problem, we're seeing it ... and it is a very much a fused problem."*

Participants spoke about specific policy outcomes from the Dashboard and highlighted that child and adolescent mental health (CAMH) data had resulted in more CAMH specific clinicians being provided in headspace clinics. Similarly, participants mentioned that data showing an increase in eating disorder presentations to the eating disorders helpline [the Butterfly Foundation helpline] led to increased funding for crisis lines.

Policy outcomes, participant 3: *"the whole process has highlighted children and young people and so there's been a number of initiatives there that have occurred ... so we've put I think CAMHs clinicians into headspaces and it's sort of meant to provide a surge capacity... the eating disorder stuff that's received some additional funding and there's also been a matched funding thing... There's been a bit more money go to some of the crisis lines as well and demand for those is sort of certainly up so Beyond Blue, Lifeline, Eating Disorders Helpline."*

Other participants also discussed the Dashboard and how it has highlighted eating disorders as an important issue at the state and federal level which has since lead to a policy response.

Participant 6: *"there's been a lot of concern about eating disorders and the impact on eating disorders and that was, you know where there was a need for, you know, there was some discussion happening at a national level and at a state level about what should be the right responses... there was an opportunity to kind*

of quickly compare and we all had to do a little bit of data development it wasn't data we all had... we were able to kind of quite quickly, you know, go away, get some data and bring it back and have a kind of consistent and informed view that went to the two state governments and the commonwealth. That was part of the discussions about policy response."

Participants discussed the fact that the Dashboard was a useful tool that was consulted by the National Cabinet when making decisions about lockdowns and the impacts lockdowns have on the mental health of people in those states.

Participant 5: *"In particular, during the lockdowns in Victoria, I know that National Cabinet was looking at the placemat data and kind of got feedback that it was very much informing deliberations. And, I think, you know, obviously the mental health impacts are, you know, right up there in terms of making decisions about whether to lockdown. And so, having evidence about the extent to which that's true, I think has been really important."*

Other participants said that although the Dashboard was not necessarily being useful for their own policy work (because they have access to other data sources) it was useful at senior levels of government. More specifically, participants discussed the fact that the Dashboard helps to build momentum and can generate policy responses at senior levels of government.

Participant 8: *"it's not hugely useful for our policy work partly because we have the original and very strong relationships with AIHW and others. That said, I think there is probably a benefit to it... there is an insatiable appetite for data, particularly at senior levels of government, at those ministerial levels, so it feeds that appetite, whether or not there is use and you know, what happens as a consequence, is questionable. I think it certainly helps to, you know, depending upon what the data is showing, it helps to build momentum in certain spaces, so I think seeing the data on a page where it is concerning, where there is a consistent trend, does get traction sometimes at ministerial levels, so that you then get tasking or, you know, a follow up question that forces a level of kind of policy thinking and response."*

7.3.3.4. Improvements to the Dashboard: online Dashboard platform

Participants were asked what they thought could be improved about the Dashboard to assist in decision making. Participants highlighted that having the Dashboard as an online platform would improve its usefulness.

Participants discussed the need for the Dashboard to be more interactive to allow users to drill down into more detailed data. This would avert the need to produce multiple A3 Dashboards to capture multiple data "cuts".

Participant 5: *"I think, where we need to get to, is more of a web-based sort of set up so that you can drill into more detail more easily. It's a very manual process at the moment and there are, sort of, certain things in the placemat [Dashboard]. Like, just this morning I was talking about the HeadtoHelp data, the Victorian clinics that were established late last year, and so we've got a kind of cumulative total in there but we know that service activity has picked up quite steeply so being able to kind of see a time series of that would be really helpful. But, as soon as you kind of go there, all of a sudden, you've got 10 A3s and you know it's too much. So, I think having a different way of interacting with the data so that we can understand it better that's the biggest improvement that I'm looking forward to occurring."*

Participant 9: *"in terms of the frequency of it, and the administrative burden. It might be that it's easier to actually put some effort into building it within something like the Suicide and Self-harm Monitoring System so*

it's more interactive, and then people have the opportunity to kind of delve deeper into stuff that they're actually interested in. Rather than having to do every single aspect of it every fortnight."

Participants discussed that having the national Dashboard and state Dashboards in a central accessible location would be useful.

Participant 6: *"part of the way that we share in NSW, in our departments, is attaching the Commonwealth reports to the distribution of the NSW report so that people receive those commonwealth reports at the same time... if there is a way to have a platform or accessibility to those things you know even across jurisdictions... we're receiving the Victorian report you end up with a lot of information over, you know, over a year now, all our reports, all the Victorian reports, several commonwealth reports you know having them in a location that could be accessible to all would be useful."*

7.3.3.5. Improvements to the Dashboard: continuation and increase in data sharing

Participants were asked questions whether they thought additional data could be included in the Dashboard that would make it more useful. They emphasised that the benefits of the Dashboard have been in improved data sharing and highlighted that further data sharing and collaborations would improve its usefulness.

Participants noted that interpretation of consent processes and legislation can 'muddy the conversations' about how data can be shared. Specific reference was made to headspace data and how this is something the states and territories would like to access.

Participant 5: *"the Department has headspace data now in the minimum dataset and because of our capability we're not generating as much value out of having that data as we should... I feel like headspace is a big gap, it's something the states they do want access to it. headspace are kind of more, you know, it's that classic thing with data sharing where so called interpretations the consent and legislation can kind of muddy the conversations about how the data could be shared and used so I think we've got a bit to work through there."*

Participants from state governments made specific reference to wanting access to headspace data in addition to PBS data including alcohol and other drugs data.

Participant 3: *"We would like, if it's possible, to include headspace data. So, we know that there's issues with children and young people and you know that's the group that they support. So, that's currently not included and so, that would be I think a really useful addition, it just would sort of add to the picture in a helpful way. We'd also be interested in, and we did ask for it, PBS [Pharmaceutical Benefits Scheme] data and including alcohol and other drugs data."*

Participants acknowledged that progress to date had been impressive but highlighted the benefits of increased efforts to share unlinked and linked unit record data and additional aggregate data.

Participant 7: *"there's discussion going on at the moment, with national agreements, about data sharing, so I think building on this, it's not a criticism because it's taken a lot of pushing to get this much data sharing. So, it's kind of opened the door and you can see the benefit. And, I think the sharing of unit record data both unlinked and linked would be you know definitely the direction we should be heading but even sharing of additional aggregate data, you know, there's still value in that too."*

Participants discussed the benefits of being able to work with other similar states and territories to understand their data and their methods of reporting.

Participant 6: *“part of the value of this is that it’s been small, and for a big state like us, you know being able to just liaise with Victoria and Queensland, is really where most of the value is, you know, and no disrespect to our colleagues in the Northern Territory or Tasmania but they’re so different in jurisdictions. So, almost having peer groups effectively.”*

7.3.3.6. Added value and continuation of the Dashboard

Participants were asked about whether the Dashboard replaces other systems that have previously been used for accessing data. Participants discussed the value of the Dashboard as an addition to rather than as a replacement for other systems.

Participant 1: *“[...] yearly reporting will still have a place, but that yearly reporting will be more about what are the long-term trends that we’re seeing as opposed to this is the number for 19–20, and still I think in some case we’re still getting the 19–20 data 13 months later. This kind of gives it a contemporary nature, so I think it very much replaces a lot of the rudimentary packages of that yearly reporting, but it does also create space to do a lot of that trend analysis that is also very important. You kind of do want it, we want to know whether the community has been suffering versus three months ago, six months ago, twelve months ago, but we also, like it’s useful from a public policy perspective to know what’s changed over the last 10 years, 15 years, 20 years, that stuff is really useful too.”*

Participants discussed the need for the Dashboard to continue beyond the COVID-19 pandemic. They agreed that it should be continued to assist policy makers

Participant 1: *“Without a doubt, to be honest I don’t think kind of, I don’t see a world where it would stop because it’s actually useful for decision makers, and if the public service produces something that’s useful for decision makers, then we should just continue to do it.”*

Participant 3: *“I think everybody wants to keep going and everybody wants to write it into the new national mental health agreement that’s sort of starting with a bilateral agreement with Victoria, so we didn’t used to do this and I think it is very useful. It started off weekly and then when things calmed down a little bit it went to fortnightly but particularly while the world is so disrupted, I think it’s very helpful.”*

Participants noted that the Dashboard provided a model that could be translated to other areas of social policy, beyond mental health and suicide prevention.

Participant 1: *“Often in the social policy space, we go ‘nope this stuff is reported once a year, it’s always been reported once a year and it will continue to be reported once a year’. This kind of goes, ‘nope, social policy reporting is doable at a much higher cadence than what we’ve previously done, and it’s useful at a much higher cadence than what we’ve previously done as well’. So, one of my hopes from this piece of work is that other parts of social policy can go ‘ah we can do a similar thing in our space’.”*

8. Routinely collected analytics data

8.1. Our approach

We worked with the AIHW to gather routinely collected analytics data from the Published Site. This was a supplementary data source for the evaluation. The Published Site went live on 29 September 2020, and website analytics data have been collected, collated and analysed at points in time by the AIHW. The AIHW shared summary documents of these data with our team in February 2021 and then again in October 2021. The summary documents provided information on Google search behaviour and traffic to the Published Site as well as user interactions with the site from when it was launched to 30 January 2021 and for the period from 1 April to 30 September 2021. Table 8 below provides an overview of key metrics and insights noted for specific time periods and, where applicable, commentary on notable changes over time.

8.2. Key Findings

Table 8 below provides an overview of key metrics and insights noted for specific time periods and, where applicable, commentary on notable changes over time.

Table 9: Summary of AIHW website analytics data and insights into the Published Site.

Website performance and use	Data and metrics	Insights
Published Site traffic	Clicks and impressions for AIHW suicide related content peaked in August 2020 (more than 1,500 daily clicks) and in September 2021 (approximately 3,000 daily clicks).	Peak periods of search activity for ‘Suicide rates 2020/2021 in Australia’ or related searches have coincided with periods of COVID-19 extended lockdowns. The first peak coincided with the Victorian COVID-19 extended lock down period and the second larger peak coincided with the NSW and Victorian extended lockdowns in 2021.
	Traffic to the Published Site has grown over time and surpassed other AIHW suicide data webpages.	Between November 2020 and September 2021, there has been steady growth in google traffic directed to the Published Site compared to other AIHW suicide related content. The Published Site is now the most popular destination for google searches on ‘Suicide statistics in Australia’ surpassing traffic to the AIHW ‘Australia’s Health snapshots: Suicide and Intentional Self-harm which was launched prior to the Published Site.
	From 1 April to 30 September 2021, there were 213,837 new visitors and 44,881 returning visitors.	New visitors to the Published site exceeded return visitors to the site which is likely to reflect the google traffic patterns and growing public awareness of the site in the first year of operation. The returning visitor to new visitor ratio is 20% for the six-month period. Returning visitors to websites usually reflect those who are more deeply engaged with the subject matter and/or are using the information for a specific purpose.
	The ‘Suicide deaths over time’ and ‘Data from suicide registers’ are trending pages	Page views to ‘Suicide deaths over time’ and ‘Data from suicide registers’ exceeded page views to the AIHW home page at points in time between July and September 2021. The

	<p>within the broader AIHW website.</p> <p>Users of the Published Site, as a proportion of all AIHW website users, have more than tripled between April and September 2021.</p>	<p>AIHW home page is usually the most popular page on the AIHW website. This signals that there has been significant public interest in suicide data and information in 2021.</p> <p>Between April and June 2021, 3.7% (3-month average) of AIHW users, used the Published Site. This has grown to 14.7% (3-month average) between July and September 2021. The Published Site is becoming more prominent as an AIHW asset.</p>
Published Site page views	<p>More than 14,000 unique page views each for the Published Site 'Home' page and 'Deaths by suicide over time' pages between 29 September 2020, and 14 February 2021.</p>	<p>The top five viewed pages within the Published Site for all users between 29 September 2020, and 14 February 2021, in order of number of views were; the Published Site 'Home' page, 'Deaths by suicide over time' page, 'Data home' page, 'COVID-19' page, and 'Data downloads' page.</p>
	<p>More than 100,000 unique page views each for 'Data from suicide registers' and 'Deaths by suicide over time' pages; more than 40,000 unique page views for the Published site 'Home' page; more than 30,000 unique page views for the 'COVID-19' page between 1 April and 30 September 2021.</p>	<p>The top five viewed pages within the Published Site for all users between April and September 2021, in order of number of views were; 'Data from suicide registers', 'Deaths by suicide over time', the 'Home' page, 'COVID-19' page, and 'Suicide among young people' page.</p> <p>In 2021, there have been more views of the 'Deaths by suicide over time' than the 'Home' page. There is also a lot of traffic to 'Data from suicide registers' and 'COVID-19' pages. Google ranking of webpages influences unique page views. A lot of traffic is being diverted to the 'Deaths by suicide', 'Data from suicide registers' and 'COVID-19' pages. This has implications for how a visitor first lands on the Published Site and what associated content they see and do not see if they enter via a specific page. Ensuring safety notices are included on each page (e.g., warnings, explanatory text and signposting to services), contextual information on the project is provided briefly on each page and supporting navigation back to introductory pages is an important consideration.</p>
	<p>Between 1 April 2021 and 30 September 2021, new visitors and return visitors mostly viewed the same pages though new visitors included 'Suicide deaths by states and territories' in their top five pages viewed while return visitors included 'Suicide and Indigenous Australians' in their top five pages viewed.</p>	<p>New and return visitors favour most of the same pages on the Published Site though there are some differences in the order of ranking of page views, and return visitors appear to be showing more interest in the 'Suicide and Indigenous Australians' page. For both new and return visitors, views of 'Death by suicides' and 'Data from suicide registers' received more views than the 'Home' page.</p>

Published Site page views by category	More than 20,000 aggregate views of data pages on the Published Site related to suicide between 29 September 2020 and 14 February 2021.	Data pages and research and information pages related to suicide were the most viewed categories (together about 90% of all aggregated views) compared to pages about intentional self-harm, psychological risk factors, and behaviours and risk factors.
	More than 300,000 aggregate views of data pages on the site related to suicide between 1 April and 30 September 2021.	'Suicide by local areas' was the most popular geographic data page and was within the top 10 most popular pages on the Published Site for both data collection periods (29 September 2020 to 14 February 2021, and 1 April and 30 September 2021).
Time on page	For both data collection periods, return visitors averaged one minute longer overall for time spent on the top 25 pages on the Published Site compared to new visitors.	New visitor and return visitors have different user behaviour with return users spending more time on average viewing and interacting with the most popular pages.
	Return visitors engage for longer periods of time (more than four minutes per page) with more in-depth materials on the Published Site including the 'Suicide in young people', 'Psychosocial risk factors for suicide', 'Suicide in Indigenous Australians', and 'Suicide by remoteness area' pages.	Return visitors appear to be interested in suicide in specific populations and geographical regions as well as some of the more in-depth analyses and research presented on the Published Site that explores psychosocial and behavioural risk factors for suicide.
User engagement on popular pages of the Published Site	Based on heat mapping analysis using 'Site Improve' (for the period 1 April to 30 June 2021), the two most utilised links on the 'Deaths by suicide over time' page were the 'Next page' link and the AIHW 'Menu' link.	The popularity of the 'Menu' link may be signalling that new users think this is the gateway to navigation around the site, instead of the true gateway which is the 'Data' navigation down the left side of the page. To help new users locate where to navigate from on the Published Site, the title of the 'Data' navigation could be changed to 'Links to data' or 'Suicide and self-harm data' or 'Data menu'.
	Based on heat mapping analysis using 'Site Improve' (for the period 1 April to 30 June 2021) for the 'Home' page, the most utilised link was the 'Data' link as part of the top menu. This link was utilised more than the main	The 'Data' link outperformed the 'Monitoring data' link despite the latter being highlighted and encased in a coloured box to attract attention. 'Scrollmap' technology confirmed that users are not scrolling down as far and therefore the top menu 'Data' link is catching users first. While these links both lead to the introduction data page 'Suicide & self-harm monitoring data', the AIHW may want to consider whether it shifts the main link further up the page, by restructuring the size and

	<p>'Monitoring data' link, further down the page.</p>	<p>location of other content on the landing page, if it wants this to be the prominent link.</p>
	<p>The heatmap also highlighted activity on the 'Need help now' link at the top right corner of each page. Between 1 April and 30 September 2021, there were 969 visits to the crisis support page with approximately 170 clicks on crisis and mental health support organisation links including Lifeline, Suicide Call Back Service, Mensline, Kidshelpline, Head to Health, Standbysupport and BeyondBlue.</p>	<p>The prominent link to the crisis support page is being used. Some visitors do click through to various crisis support organisations.</p>
<p>Referral traffic</p>	<p>Between 24 December 2020, and 20 January 2021 Google search directed 96.5% of traffic to the most popular page 'Deaths by suicide over time'. There was a fractional number of referrals from other sources (0.3%).</p> <p>Between 24 December 2020, and 20 January 2021 72.8% of referrals to the 'Home' page came from Google while direct links (i.e., bookmarking or links created) accounted for 12.4%. Referral from the National Mental Health Commission website accounted for 4.3% (combining 3.6% and 0.7% from different links on the website) of all referrals and Bing accounted for 1.6%. Other sources individually provided between 0.3% and 1.5% of referrals.</p>	<p>Google was the main referrer of traffic to the Published Site whether it be the data pages or the 'Home' page. Referrals to the 'Home' page from another search database, Bing, grew slightly from 1.6% in January 2021 to 3.6% in September 2021.</p> <p>Referral from direct links to the 'Home' page has more than doubled (from 12.4% to 29.5%) between January and September 2021. As direct links include referral from bookmarking of the Published site in users Google platform and links created, this may suggest that people are wanting to return to the Published site and engage with it on a regular basis or they are sharing the link readily with other people.</p> <p>Some referral traffic is coming from the National Mental Health Commission website. It has increased slightly between January and September 2021 from 4.3% to 5.4%. The small number of referrals might be related to the location and prominence of communications and links to the Published site on the National Mental Health Commission website. Referral traffic from other sector related organisation and government websites is very small (between 0.2% and 0.6%) as of 30 September 2021.</p>

Between 1 April and 30 September 2021 86.9% of directed traffic to the most popular page 'Data from suicide registers' came from Google with 5.5% from direct links.

Between 1 April and 30 September 2021, 48.6% of referrals to the 'Home' page, came from Google, 29.5% from direct links and 5.4% from the National Mental Health Commission. Bing accounted for 3.6%. Other sources individually provided between 0.2% and 1.9% of referrals

9. Discussion

9.1. Summary of main findings

9.1.1. Development of the System and related Project activities

9.1.1.1. Key impacts

The Published Site went live in September 2020 and is tangible evidence of the Project producing this important output. It was envisaged as a 'one stop shop' for national suicide and self-harm data in Australia and is now the most comprehensive resource of published data and information on both suicide and self-harm available to the public. It is also unique as no other system globally appears to bring together suicide and self-harm data and information into a consolidated system. The Published Site has resulted from a significant amount of technical project activity by the AIHW related to data management and reporting, but also ongoing development of content and maintenance. Between the initial release of the Published Site and 31 October 2021, there were eight major website updates which included the addition of 17 more visualisations. These updates have added recent data to tables, visualisations and information and included updates to data about deaths by suicide in Australia over time, international self-harm hospitalisations, ambulance presentations for self-harm, and population and geographic specific data on suicide and self-harm. Some of these data have been published on the site within one to two weeks of updated source datasets being released by relevant data custodians, which is a significant achievement as it has required intensive activity by the AIHW.

Additionally, throughout the Project, the AIHW, together with the National Mental Health Commission and the Australian Department of Health, have leveraged their sector relationships and networks with data custodians, government departments, people with lived experience of suicide, and the broader sector to conduct point-in-time consultation or seek ongoing input from advisory and working groups. These 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. Stakeholder consultation appeared authentic and productive, evidenced by high rates of participant engagement at meetings and ongoing participation. The importance of the lived experience perspective to guide the development of the System was especially prominent, reflecting the genuine commitment of the Project team to ensure that key decisions about the System were informed by the voices of people who have been affected by suicide. Consultation with people with lived experience has been extensive and is now an embedded and ongoing aspect of the System. Lived experience participants have felt heard, respected and valued. They have appreciated the authentic and positive new ways of working that have emerged as part of the Project. There is potential to utilise this additional leadership of the 'Director of Lived Experience' at the National Mental Health Commission, to guide further development of the role of lived experience within the System over time.

In relation to the Portal, a minimal viable product has been developed and undergone initial beta testing. However, advice from the EAG 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 (e.g., PHNs) and the development of a working group dedicated to drafting guidelines for the Portal to occur in parallel with its early development. Although this additional consultation has extended timelines for the implementation of the Portal, this has occurred because the EAG aptly identified a number of complexities and challenges to the development and implementation of the Portal. These include the lack

of precedents for this type of product; the need to be transparent with the sector as to who is able (and not able) to access the Portal and what data are housed in it; and the scope of the Portal offering and what is directly managed by the AIHW versus other organisations such as the National Mental Health Commission. The guidelines have emerged as a tool to help govern what data are likely to be housed in the Portal compared with the Published Site, as well as the access and use of the Portal when implemented. Additional advice provided and complementing the guidelines, has focused on the application of the guidelines for the Portal. As of November 2021, consultations with PHNs and other groups have been conducted, and the draft guidelines have been developed by the Portal Working Group and will be presented to the AIHW in December 2021 for review. The Portal Working Group has also considered how other suicide or self-harm data systems are accessed and operate in Australia and internationally, including the National Coronial Information System and the Danish Data Linkage System.

The Published Site and the Portal prototype are tangible products of the System, but the Project has had other achievements too. It has involved an additional six streams of project activity (see Figure 2). 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 also emerged that have supported intra- and inter- government data sharing, and subsequent policy and planning. The impacts of some of these activities are further discussed below as they relate to the assessment of attributes of the System.

There has also been a deliberate effort by the AIHW with the National Mental Health Commission to develop a continuous quality improvement framework (the Framework) to guide quality improvements and sustainability of the System over time, although this is not due to be implemented until June 2022. As part of the development of the Framework, the Project team have recognised the need to monitor and measure processes, impacts and outcomes of the System as initially reflected in the program logic (see Section 3.3) developed to guide this evaluation. At the National Mental Health Commission Lived Experience Working Group meeting in November 2021, the Project team also introduced the Continuous Improvement Framework and the evaluation program logic to the group to seek their input, emphasising a commitment to ensuring that the Continuous Improvement Framework incorporates measurement of what is important from the lived experience perspective.

9.1.1.2. 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. Throughout the evaluation period, the scope of the Project activities (and what the System encompasses) has increased. This has occurred in response to external factors such as the COVID-19 context, and the AIHW leveraging existing research and data development projects for the System, and heeding advice from the Project leadership and management to expand stakeholder consultation to inform aspects of the System. 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 Improvement Framework encapsulates monitoring of the System's ongoing performance and how this information then feeds into strategic planning for further development.

The AIHW will also need to consider the results and recommendations of the PHN portal consultations and all aspects of the Portal draft guidelines in the context of its own governance structures and requirements. It will also need to consider the operational capacity, capabilities and resources available for the development of the Portal and System overall.

Stakeholders with lived experience of suicide who were interviewed during the evaluation noted that although they were comfortable providing feedback and felt that they were listened to, they did not always know whether or how their feedback had been incorporated into the System. Lived experience participants suggested that if feedback hadn't or couldn't be incorporated, that this should be communicated to them.

9.1.2. System performance: data quality and sensitivity

9.1.2.1. 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. For public health surveillance systems to be useful they must house high quality data and information. 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 also 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, along with regular viewing of the Published Site by our team over the course of the evaluation period, also revealed tangible evidence of ongoing efforts to publish data on instances of suicide and self-harm for different geographic regions (including at the PHN level) and specific population groups (such as young people, Australian Defence Force personnel and Indigenous people) to increase the representativeness of the data presented. There has also been increasing content on behaviours and risk factors associated with suicide to support more nuanced understanding of the factors that may increase risk of suicide in individuals and communities.

9.1.2.2. 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, jurisdictions, and over time. These and other inconsistencies in data reporting are issues that the Project seeks to improve through data development activities (see Section 4.2), however the impact of these and other data improvement activities will require time to further improve the accuracy and consistency of these data across Australia.

Representation of population sub-groups (particularly those that are over-represented in suicide and self-harm statistics) is 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 already commenced work to add additional sources of information for specific population sub-groups (e.g., working with Latrobe University to publish data from the Private Lives 3 survey on the health and wellbeing of Australian LGBTIQ+ people (26)).

9.1.3. System performance: simplicity

9.1.3.1. Key impacts

Simplicity refers to the structure and ease of operation of the System for users. Based on interviews with those involved in the design and development of the Published Site and those who have used the site, there was a high level of agreement 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 publication of data (especially for updates to existing data). This is also likely to have impacted on the timeliness of reporting of data (see Section 5.3).

9.1.3.2. 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 communication of the data not available on the site (i.e., data on suicide or self-harm in the LGBTIQ+ population).

9.1.4. System performance: timeliness

9.1.4.1. Key impacts

Timeliness refers to the speed between steps in the System and the availability of information for use for public health planning and intervention. A notable impact on the timeliness of the System to date 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. They have 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 them to establish registers. As at November 2021, nearly all states and territories have established suicide registers. The data from suicide registers have been especially useful for governments to monitor the impacts of COVID-19 and associated lockdowns on suicide in Australia, including dispelling myths about increases in suicide that have been reported in the media.

In a similar vein, the publication of National Ambulance Surveillance System data has provided a timelier source of data on self-harm and suicidal behaviours in the community than data from the National Hospital Morbidity Database which has a 12-month lag. These data were included in the reporting to the National Cabinet and Prime Minister's Office through the Dashboard, which was the subject of Case Study 2.

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 and so 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. Therefore 2020 deaths by suicide data, released in late September 2021, has already been added to the Published Site. This is in contrast to how quickly suicide and self-harm data from 2019 had been updated for the Published Site or even for other AIHW products previously reporting on suicide and self-harm which provided more one-off static pictures in 2019 of suicide and self-harm.

9.1.4.2. Challenges

It is important for prevention efforts for data to be available in a timely matter and the traditional delay of suicide and self-harm data release is known to hamper prevention efforts. 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 through work with timelier sources such as suicide registries and ambulance data, as well as in-house process improvements to expedite publication of data.

9.1.5. System performance: accessibility

9.1.5.1. 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 structured well and therefore more accessible than some other government websites which require greater technical knowledge. There was consensus from various end-users (such as researchers and PHNs) 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 and that this was a great improvement from how things had been done previously.

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. Dissemination included running specific events with stakeholders to report results and providing opportunities for feedback. Other dissemination efforts included publications of the data through annual reports or journal articles, or even facilitating governments or custodians of data at regional levels to disseminate the data to those working in suicide and self-harm prevention within their specific region.

9.1.5.2. 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 different levels of data knowledge and capability, and facilitates a range of different uses. Participants linked accessibility with data being interpretable too, 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 and beneficiaries of the System (e.g., young people) in order to inform the ongoing design of the System to ensure that it is accessible to these groups.

PHN stakeholder views captured in interviews and in Case Study 1 expressed 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.

Interview participants reflecting on international suicide or self-harm systems noted that where systems included restricted access to some of the data within their systems, these systems also built-in processes to understand data capability of those applying to access and use these data. This vetting of access based on data capability may be relevant for administration of access to the Portal. Additionally, some international participants mentioned that system developers also took on knowledge translation and knowledge brokering roles where they provided tailored data and interpretation of these data in response to specific requests. This enabled improved access and use of data from systems. Whilst this may be a worthwhile way of increasing the accessibility of the System, it will add a further stream of activity for the AIHW.

9.1.6. System performance: acceptability

9.1.6.1. Key impacts

The acceptability of the System refers to the willingness of persons and organisations to use the System. This includes end-users as well as those collecting or providing access to the data. 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.

Participants representing international suicide and self-harm systems noted the importance of maintaining communication and working relationships with those collecting or providing access to the data. They also noted that efforts required to build and sustain relationships with data custodians varied greatly from region to region for national systems. Data custodians 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.

9.1.6.2. Challenges

Based on information from interviews with stakeholders from PHNs, local council and NGOs, 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 – closer to the level of granularity intended for the Portal. Stakeholders from LGBTIQ+ advocacy organisations who were interviewed also raised concerns about the lack of data on the Published Site to help inform their suicide and self-harm prevention efforts for their populations who are at higher risk of suicide compared to the general population.

Data custodians raised a number of challenges that they perceived had an impact on the extent of their involvement in providing data to the System. These included: 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.

9.1.7. System performance: usefulness

9.1.7.1. 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. User experience and design emphasizes that products should be usable and useful to facilitate use (50).

Based on the findings from the 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 types of use. 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. The psychosocial data (i.e., information presented on the 'behaviours and risk factors' page of the Published Site) have also been useful for considering associated factors that may put people at risk of suicide, and the ambulance data from the National Ambulance Surveillance System were considered a useful addition to broaden understanding of community rates of self-harm and suicidal behaviours. 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. Stakeholders involved in the development of the System 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 already 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. The high number of visits to the 'COVID-19' page and 'data from suicide registers' page underscore the public interest in understanding mental health and suicide impacts of the pandemic. Public awareness of the site has also grown with new visitors far exceeding return visitors between April and September 2021. However, when visitors do return, they spend longer viewing content on the site suggesting a deeper engagement with the content. During this same time period, referral from direct links to the 'Home' page more than doubled. As direct links includes referral from bookmarking of the Published Site in users' Google platform and links

created, it is evident that users are wanting to return to the site and engage with it on a regular basis and/or they are sharing the link with other people.

Representatives from government departments unanimously 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 triangulation and collation of multiple government data sources including the timelier data from the System was used to inform real-time intra- and inter- governmental reporting, policy and planning discussion and responses. 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 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 from 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 due to an observed increase in eating disorder presentations. Beyond informing health related policy, there was recognition that the Dashboard was also useful for helping policy makers see issues in Australia as not just health or social or economic issues but rather ‘fused’ issues.

9.1.7.2. Challenges

Based on the stakeholder interviews, timely data were viewed as imperative for the detection of suicide and self-harm. There was also a perception from some stakeholders that while the data available in the System was a big improvement from what was previously publicly available, it might have disappointed some users of these data who had higher expectations of the timeliness of the data. 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 or new technologies and additional analytical work. This may allow for the identification of unexpected increases in suicide or self-harm and enable localised service responses.

There is some risk that public use of the Published Site may lead to misuse or misinterpretation of data.

9.2. 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.

Recommendations three and six refer to relevant sections of the recent National Mental Health and Suicide Prevention Agreement, 2022 (51).

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 incorporating it into the Portal) to improve its usefulness for government users, 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. Leveraging 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 Improvement Framework into strategy cycles for the System and project management processes to support decision making, accountability, learning and innovation.

9.3. Strengths and limitations of the evaluation

9.3.1. Strengths

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 vast individual data source findings, overall synthesis of findings and recommendations can be used to inform future quality improvements to Project processes and the System over time. The evaluation triangulated data from a broad range of sources to provide an overview of the extent to which the Project and System objectives have been achieved, including early insights into the use and usefulness of the System for suicide and self-harm prevention policy and planning.

9.3.2. Limitations

As the evaluation has been conducted early in the establishment phase of the System, 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. Within the evaluation timeframe, the evaluation was also unable to explore the performance of the Portal component of the System given its stage of development. This is also worthy of future evaluation.

9.4. 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, in line with the Fifth National Mental Health and Suicide Prevention Plan. 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 data custodians, organisations and individuals that are involved in the suicide prevention sector, 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.

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Appendix 1

Sample of information for the review of key documents and observational and participatory data.

Table 10: Events attended for observation and/or participation.

Date	Event	Participants*
04.06.2020	Published Site: Meeting of the User Experience Working Group: Workshop 1	37
10.06.2020	Meeting of the Expert Advisory Group Sub-committee for the National Suicide and Self-harm Monitoring System	29
24.06.2020	Meeting of the Expert Advisory Group Sub-committee for the National Suicide and Self-harm Monitoring System Published Site	11
01.07.2020	Meeting with the Australian Institute of Health and Welfare and the Australian Government Department of Health	6
17.07.2020	Published Site: Meeting of the User Experience Working Group: Workshop 2	39
11.08.2020	Published Site: Meeting of the User Experience Working Group: Workshop 3	33
28.09.2020	Media Briefing Webinar: Launch of the Published Site	>50
29.09.2020	Suicide Prevention Sector Webinar: Launch of the Published Site	>50
19.03.2021	The Portal consultation workshop with ACT stakeholders	24
28.04.2021	Published Site: Meeting of the User Experience Working Group: Workshop 4	19
09.06.2021	Meeting of the Expert Advisory Group Sub-committee for the National Suicide and Self-harm Monitoring System	16
08.07.2021	Black Dog Institute with SAS Institute® The Portal PHN Consultation Workshops: Group 1	20
09.07.2021	Black Dog Institute with SAS Institute® The Portal PHN Consultation Workshops: Group 2	17
13.07.2021	Black Dog Institute with SAS Institute® The Portal PHN Consultation Workshops: Group 3	18
20.07.2021	Black Dog Institute with SAS Institute® The Portal PHN Consultation Workshops: Group 4	16
10.08.2021	Black Dog Institute with SAS Institute® The Portal final presentation of consultation findings and recommendations to all PHN groups	24

13.09.2021	Published Site: Meeting of the User Experience Working Group: Workshop 5	42
15.09.2021	The Portal Working Group: Meeting 1	22
01.10.2021	The Portal Working Group: Meeting 2	18
20.10.2021	The Portal Working Group: Special presentation of the National Coronial Information System and the Danish Linkage Data	26
21.10.2021	The Portal Working Group: Meeting 3	23
03.11.2021	The Portal Working Group: Meeting 4	21
10.11.2021	National Mental Health Commission Lived Experience Working Group Meeting	21
18.11.2021	The Portal Working Group: Meeting 5	21

*Approximate number of participants based on video conferencing counts at commencement of the meeting.

Table 11: List of stakeholder groups represented through participation in meetings and workshops.

Stakeholder groups
Australian Institute of Health and Welfare
National Mental Health Commission project
Department of Health
The Expert Advisory Group Subcommittee of the National Suicide and Self-harm Monitoring System
Primary Health Networks
People with a lived experience of suicide and/or self-harm including those bereaved by suicide
State and territory government departments
Black Dog Institute and SAS Institute®
Non-Government Organisations involved in suicide prevention
Community organisations working in the suicide-prevention area including advocacy groups
Data custodians
Members of Suicide Prevention Australia
Service providers including those from youth focused mental health services, crisis, and other mental health support lines
Advocates of Indigenous people's health and wellbeing
Researchers working with suicide and self-harm data and/or suicide prevention more broadly
University of Melbourne evaluation team members

Table 12: List of the types of documents included in the review.

List of the types of documents included in the review.
AIHW project planning documents, internal memos, and presentations.
Expert Advisory Group briefing documents and meeting minutes for meetings: November 2019, March 2020, June 2020, September 2020, December 2020, March 2021, June 2021, October 2021.
User Experience Working Group workshop briefing documents and access to wireframes and tableau visualisations as part of the workshops: workshops 1–5.
AIHW written updates on data development activities.
AIHW written reviews and approvals plans: business processes for embargo and non-embargoed content on the Published site, July 2021.
AIHW progress reporting to the DoH: progress reports 3 and 4.
AIHW and NMHC media and sector briefing documents and media pack.
Black Dog Institute and SAS Institute® PHN State and Territory Information Portal consultation presentations.
Black Dog Institute and SAS Institute® PHN State and Territory Information Portal consultation final report.
The Portal working group briefing documents and meeting minutes for meetings: September 2021, October 2021, November 2021.
National Mental Health Commission Lived Experience Working Group meeting briefing documents for the meeting: November 2021.