

National Suicide and Self-Harm Monitoring Project and System:

Data Requirements for the Portal

9th November 2021

FINAL Report



Produced by:

Phillippa Butt

Matthew Phillips

Johnny Chen

John Kershaw

Janey McGoldrick

Contact Details:

p.butt@blackdog.org.au

John.kershaw@sas.com



Contents

Contents	2
Use of Terms	5
1. Executive Summary	6
1.1. Key Messages	6
1.2. Background and Context.....	7
1.3. Approach	8
1.4. Main Findings	8
1.5. Conclusion.....	9
<i>DESIRED FEATURES AND FUNCTIONALITY OF THE PORTAL</i>	<i>11</i>
2. Key Recommendations for the Portal	13
3. Introduction and Background	15
3.1. The National Suicide and Self-Harm Monitoring Project	15
3.2. The Journey So Far	16
3.3. Objective of this Report	17
3.4. Approach	18
3.4.1. Workshops.....	20
3.5. Role of Primary Health Networks in Suicide Prevention	23
3.6. National Suicide Prevention Trial Context	24
4. Current State View.....	26
4.1. Data Assets currently utilised	26
4.2. How is Data currently utilised?	28
4.3. Significant Challenges.....	29
5. Preferences for the Future.....	31

5.1. Future Data Preferences	31
5.1.1. Desired Data Sources.....	31
5.1.2. Desirable Insights, Priority Populations, and Risk Factors.....	32
5.1.3. Utility of New Data.....	35
5.1.4. Delivery of New Data	36
5.2. Specific Differences by PHN	38
5.2.1. Demography.....	38
5.2.2. PHN Organisational Differences	40
5.3. Opportunities to Address Data and Analysis Needs	41
5.3.1. Timeliness	42
5.3.2. Granularity	43
5.3.3. Priority Populations	44
5.3.4. Risk Factors.....	45
5.3.5. Analytics	47
5.3.6. Data Linkage	50
6. What Happens Next?.....	52
6.1. Key Milestones and Roadmap	52
Appendix A. Workshop Details	53
A.1. Pre-Workshop Survey Responses.....	53
A.2. Prioritising Data Needs (Ranking Poll Survey Results).....	61
Appendix B.....	62
B.1. Data Sources.....	62
B.2. Lived Experience Advisor Feedback and Comments.....	63
B.3. Workshop Attendees	64

Figure 1: Suicide Prevention Pathway 10

Figure 2: Project Approach..... 19

Figure 3: Word cloud illustrating the type of suicide data or data sources PHNs would like to have. The size of the words represents the frequency of occurrence..... 31

Figure 4: Word cloud illustrating desired insights, trends, and information by PHNs. The size of the words represents the frequency of occurrence. 33

Figure 5: Word cloud illustrating the specific priority populations and risk factors that PHNs want to know about (the size of the words represents the frequency of occurrence)..... 34

Figure 6: Word cloud illustrating what PHNs will use new data to inform in their suicide prevention strategy. The size of the words represents the frequency of occurrence..... 35

Figure 7: Pie chart showing percentage breakdown of the data presentation/analysis PHNs would like to see from the Portal..... 37

Figure 8: Pie-of-pie chart illustrating the two desired usages of Portal data (sharing/informing and further analysis) mentioned by PHNs and which type of parties the data will be shared with. 38

Figure 9: Typical progression of analytics maturity. 48

Figure 10: Activities and initiatives for data related activities over time horizons. 52

Version	Author(s)	Date	Summary of change
DRAFT Version 1.0	Philippa Butt, John Kershaw, Johnny Chen	23 rd August 2021	Initial Draft
DRAFT Version 2.0	As above	9 th November 2021	Feedback from AIHW

Use of Terms

Terms	Definitions
Suicide and Self-Harm Monitoring System (The "System")	The National Suicide and Self-Harm Monitoring System brings together existing and new data on suicide and self-harm.
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 <i>Suicide & self-harm monitoring</i> website. Phase 2 is the development of the State and Territory Information Portal (the Portal).
The monitoring website (The "Website")	Brings together existing and new morbidity and mortality data related to suicide and self-harm from across Australia into a public website that will provide interactive data visualisations, geospatial mapping and information on current suicide prevention activities and services.
Phase 1	Development of the <i>Suicide & self-harm monitoring</i> website.
Phase 2	Development of the Portal.
Priority Populations	Groups of individuals who are at greater risk and have higher rates of suicidal thoughts or behaviour which could be caused by factors including greater discrimination, isolation, or other forms of social exclusion. Priority populations include at a very broad level, people who are Aboriginal and/or Torres Strait Islander, LGBTQIA+ communities and Veterans. People who have had a previous suicide attempt or are bereaved by suicide are also at a higher risk of suicide.
Means Restriction	Restricting access to the means or methods by which people end their life (for example firearms, toxic domestic gas, or erecting safety barriers) is one of the most effective suicide prevention strategies ¹ .
Social Determinants of Suicide	Social determinants such as poverty, unemployment, homelessness, alcohol use and domestic violence are risk factors for suicide; and their amelioration will lead to decreased suicide rates.
Risk Factors	A variable which is associated with increased risk of intentional self-harm or suicide.

¹ <https://www.blackdoginstitute.org.au/wp-content/uploads/2020/04/2019-09-16-strategy-9-research-summary.pdf?sfvrsn=8>

1. Executive Summary

1.1. Key Messages

This report is the result of consultation with the Primary Health Networks (PHNs) that were part of the National Suicide Prevention Trial (NSPT). The consultation workshops were framed to encourage PHNs to do blue-sky thinking and explore what data they would like to access in the Portal if there were no constraints. We have collated their preferences for the future of self-harm and suicide data and made recommendations based on what we have heard.

The importance of using suicide prevention data and information to inform policy development strategy and service provision is well understood by PHNs involved in this project. Through the Portal, AIHW aims to enable policy makers and service providers to identify emerging trends and priority populations to support timely policy decisions and localised planning of suicide prevention activities

Future data needs across PHNs vary significantly, this is largely aligned to population size and levels of remoteness associated with different Networks. A number of PHNs are currently at a higher level of maturity than others (with dedicated data science and epidemiology resources). Our recommendations are aimed at there being a consistent level of accessibility and usage of data nationally, increasing access to vital data and developing analytical maturity.

Granularity was a key request we heard from PHNs; they would like a breakdown of suicide attempts and deaths by demographic characteristics and geographical areas in order to tailor the commissioning of prevention activities and services for priority populations and local regions. We recognise all data in the Portal would need to comply with the AIHW data privacy policy.

The collection and access to specific data sets is seen as a significant challenge; one of the most critical data sources identified was a view of historical *suicide attempts*. PHNs highlighted that getting a definitive view of this information was very difficult. Separate sources exist that can contribute to this statistic; however, such sources are either not consistently available, not accessible in a usable format or simply not supplied in a consistent and timely manner.

PHNs also want to understand the pathways and combination of events that personas (groups of people that have common experiences, needs and stressors) experience (including both self-harm and suicide attempts, any support received before or after these experiences) over a lifetime to understand where they should focus their suicide prevention strategies and activity. Such a pathway would include events and service touchpoints pre and post suicide attempt(s). PHNs would utilize a deeper understanding of common life events, stressors and service touchpoints to implement more effective interventions. Any linked data would need to be deidentified and aggregated in line with the AIHW data privacy policy.

1.2. Background and Context

The National Suicide and Self-Harm Monitoring System is an initiative of the Australian Government that is being implemented by the Australian Institute of Health and Welfare (AIHW) in collaboration with the Department of Health and the National Mental Health Commission. The System will improve the quality, accessibility, and timeliness of data on deaths by suicide and on self-harming and suicidal behaviours.

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, which includes a commitment to improving the quality and timeliness of national data on suicide and self-harm. Improved national surveillance and data will inform mental health and suicide prevention policy makers, service providers, communities, and researchers to identify emerging areas of concern and population sub-groups. 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.

The overall project has two broad objectives:

- To build an integrated data system which will help increase the timeliness, coherence, and quality of data on suicide, suicide attempts and self-harm
- To undertake specific data development activities to improve data collection and supply pertaining to suicide, suicide attempts and self-harm.

The integrated data platform has been developed and will support two data related components, these being:

- A *Published Site* containing non identifiable, publicly available information (details of information held on the Published Site can be found in 3.2 (page 16)
- A *State and Territory Information Portal* (the Portal) to include more detailed, non-identifiable information on suicide and self-harm from existing and new data sources, it will aim to provide an analytics platform and will be available to data custodians and vetted users only, to help them identify emerging areas or priority groups of concern

This report focuses on the findings from a series of workshops and meetings with a range Primary Health Networks (PHNs), see Section 3.5 with the purpose of understanding the following:

- Assessing current data usage and experiences in accessing data sources including the Suicide and Self-Harm Monitoring Project public website
- Understanding future preferences of PHNs for the Portal, specifically, identifying additional and complimentary data sources likely to be most useful in assisting with planning, prevention, and intervention strategies

1.3. Approach

Black Dog Institute and SAS Institute worked collaboratively on this project to identify the key future PHN preferences for the Portal. This was completed through a number structured workshops and follow-up sessions with twelve PHNs (the PHNs included were selected based on being part of the Commonwealth Government's National Suicide Prevention Trial, conducted in partnership with the Black Dog Institute).

Information on existing usage of data and desired future needs was collected and consolidated. These findings were then validated with PHNs, Lived Experience, AIHW and Department of Health personnel for clarification further comments and suggestions. All findings and recommendations are documented in this report.

1.4. Main Findings

PHNs understand the significant role data plays in creating effective local suicide prevention strategies, planning for services, and gaining a deeper understanding of different population cohorts at elevated risk of suicide. There were variable levels of maturity in the access to, and usage of self-harm and suicide data across the PHNs.

A wide range of data is currently accessed, with the AIHW website, ABS, and coronial and registry data (including National Coronial Information System (NCIS) being the most common, with all consulted PHNs using at least one of these three sources.

PHNs identified that there are a significant number of touchpoints where community members have contact with mental health and suicide prevention services, but either the data is not being consistently collected or PHNs do not have access to the data. We heard from a number of PHNs that they did not consistently have access to State Health data on suicide, even where comprehensive State suicide registers exist.

Figure 1 below shows a Suicide Prevention Pathway, a visual map of the potential journey's likely to be taken pre and post attempt(s) with the various touchpoint's people have with services. This highlights the opportunities for data to be collected and to better understand and support those at risk of suicide. PHNs highlighted a number areas on Figure 1 where they would like access to the data in the future on the Portal. In our consultation PHNs from different states and territories had different levels of access to data. We recommend working towards greater standardization of PHN access to data nationally on the Portal.

PHNs would like to be able to view all data through the lens of the local region, with greater geographic granularity. They would also like to be able to see the data on priority populations who are at a greater risk of self-harm and suicide.

Emergency Department presentations and hospital admissions are accessed by the majority of PHNs, however, there were issues with completeness and reliability with these data sources, as well as timeliness of receipt. This information is seen as critical in understanding suicide attempts. Lived Experience contributors highlighted that this was a considerable gap in current data.

General Practitioner data was another priority that PHNs would like to have more access to in the future; however, the lack standardization in data capturing, storage, coding and access to this data is a significant gap.

Additional data sources that were highlighted during conversations with PHNs and Lived Experience contributors included data:

- From schools (considered a key part of an individual's journey)
- From Aftercare and Safe Haven services
- On Veterans
- Captured during conversations with community supports, councillors, and other sources

Flexibility in being able to download data for further analysis is a key requirement for the Portal.

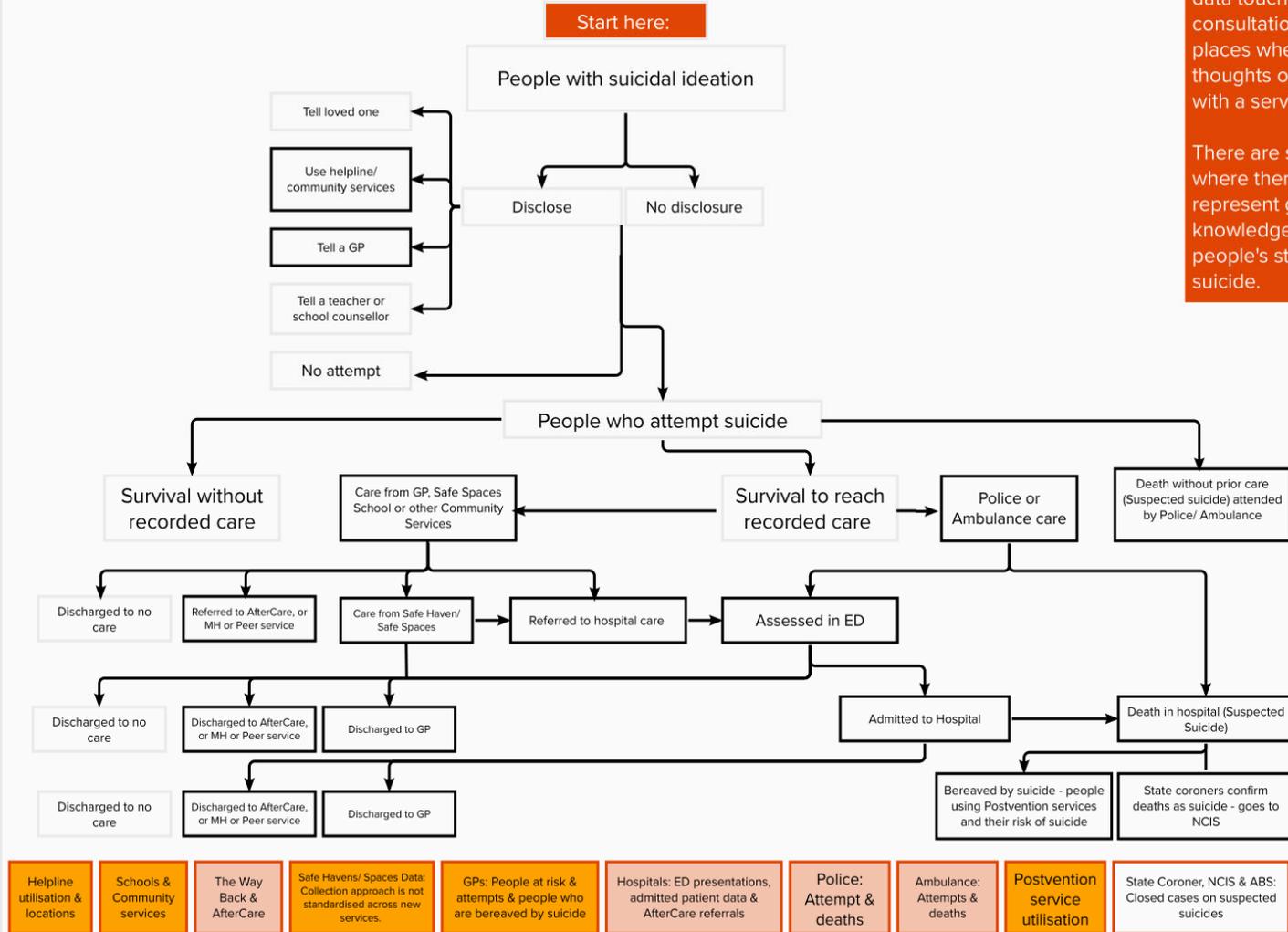
In the future, PHNs would like additional insights on the common journeys people at risk of suicide take, by linking multiple data sets, in order to identify how best to commission services and interventions. All linked data would need to be anonymized and journeys aggregated to ensure privacy of individuals was protected in line with the AIHW data and privacy guidelines.

1.5. Conclusion

A significant amount of information was captured during this project, with understanding the future desired preferences for the Portal and building on the current AIHW Public site being the key objective. More broadly we heard from PHNs how they would like data to support policy, decision making, commissioning and impact measurement of initiatives, to contribute to reducing suicide in Australia.

Figure 1: Suicide Prevention Pathway

Suicide Prevention Pathways



This visual represents the services and data touchpoints we heard from consultation with the PHNs. These are the places where people with suicidal thoughts or attempts have a touchpoint with a service and their data is collected.

There are some journeys people have where there is no data collected. These represent gaps in the data and our knowledge. This visual does not capture people's stories and lived experiences of suicide.

Desired Features and Functionality of the Portal

We asked PHNs to use “blue-sky” thinking to identify what they would like from the Portal and how self-harm and suicide prevention data could help them to better understand their community, develop suicide prevention strategies, commission services, and evaluate the impact of their activities. We have prioritized their desired features and functionality of the Portal into Horizon One, Two and Three. Those in Horizon One are the most achievable but will still require services to improve their data collection, national standardization to enable AIHW to provide the same data to PHNs in all states and territories and strong relationships with a wide range of data custodians. The desired features in Horizon 2 will require more significant improvements to service data collection and coding, and new data custodians would need to grant access to AIHW to enable sharing within the Portal. Horizon 3 represents the most significant shift with the desire to link in a timely way, multiple datasets to understand whole of life insights about different persona groups and their experience of self-harm or suicide.

Table 1: Desired Features and Functionality of the Portal

	Horizon One	Horizon Two	Horizon Three
Standardised Access to Data Sources	<ul style="list-style-type: none"> • Police Data • Ambulance Data • Emergency Department Data and Hospital Admissions on intentional self-harm • Aftercare and Postvention Referrals • Coronial Data – Suspected suicides & confirmed 	<ul style="list-style-type: none"> • Data on GP usage for suicidality • Broader data on service touchpoints including school counsellors, Safe Havens, and commissioned services 	<ul style="list-style-type: none"> • Linkage of data sets to understand common journeys
Functionality of the Portal	<p>Data to be presented by PHN region and then by local regions within the PHN.</p> <p>Attempts, deaths and means to be geospatially mapped by SA2 Level.</p> <p>Filtering data to compare rates for:</p> <ul style="list-style-type: none"> • Gender • Age 	<p>Filtering data to compare rates for:</p> <ul style="list-style-type: none"> • LGBTQIA+ status • Increased accuracy on Aboriginal and Torres Strait Islander status <p>Improved filtering functionality</p>	<ul style="list-style-type: none"> • Analyse local aggregated linked data sets to understand personas and common journeys • “What if” tool to allow modelling and deeper analysis on likelihood of

	<ul style="list-style-type: none"> • Previous self-harm history • Aboriginal and Torres Strait Islander status • Culturally and Linguistically diverse status • Veteran status • Physical health • Disability • Chronic Pain • AOD Use 		intentional self-harm given certain risk factors
Timeliness & Impact	Timely access to data on intentional self-harm and suspected suicides in addition to coronial data on confirmed suicides.	Timely data on intentional self-harm, suspected suicides, and coronial data on confirmed suicides, broken down by priority populations.	Timely linked data to understand common journeys and to identify emerging risk factors

2. Key Recommendations for the Portal

Several key recommendations are made in relation to the requirements for the Portal. Additionally, a number of more general recommendations and suggestions are made.

1. Developing a single source of truth for suicide attempts is seen as a significant PHN need. Such a data asset will be constructed from a combination of several separate sources which will require a consistent approach to collection, coding, and updates. The critical elements of such a single source of truth can be split into two groups:
 - Group One: Critical information to support self-harm, suicide attempts, and suicide deaths should focus on consistent collection of services related data, from ambulance and police.
 - Group Two: Data relating to hospital admissions and emergency department presentations; data relating to transport (where applicable, e.g., metropolitan train services).

We are aware some PHNs are accessing some of the above data sets already, particularly police attendance at suicide deaths in parts of NSW, VIC, and QLD, however, other data sets are still required and the majority of PHNs do not yet have access to such data.

This would be an opportune time to strive for improved consistency, in what is recorded and how it is recorded, in relation to the data in Groups One and Two.

In addition to the above, there is a need for data from coronial registry sources to be included, as a pivotal source in recording suicide deaths.

2. PHNs would like to receive, where possible, data in a more timely manner. This applies to the data required to form the single source of truth, PHNs would like police, ambulance and hospital data to be accessible more quickly and loaded into the Portal for early access. There was a call for “real-time” data, or, possible “near real-time” data flows. We recognize these preferences may be difficult to achieve in the short-term (next 1-2 years). We recommend a working party to investigate the feasibility of receiving more timely feeds of data from the police and ambulance services.
3. PHNs would like the Portal to support them to have a more holistic understanding of common pathways of people who have had thoughts of self-harm or suicide, intentionally self-harmed, had suicide attempts, recovered, or died by suicide. This could be achieved by linking multiple data sets to help PHNs understand the compounding risk factors and common service touchpoints and improve their interventions. The recommended data sets to help understand deidentified and aggregated pathways, include several of those recorded in Recommendations 1 and 3. Additional sources could include:
 - a. Use of community services
 - b. Domestic and family violence history
 - c. Justice system involvement and incarceration history
 - d. Employment, housing status, physical health, financial situation, socio-economic status

e. Use of helplines

4. PHNs would like the ability to filter for different demographic groups within their region, to better plan targeted services and be responsive when there are increased rates or trends within demographic and regional sub-populations.
5. A key source of data that PHNs would like greater access to data is from GPs. This was considered a significant gap in understanding levels of self-harm, depression and patients expressing suicidality, factors that may lead to further self-harm and suicide. Collection of this data has historically been inconsistent and patchy and collection methods are sub-optimal. It is recommended that GP data be a focus of opportunity, with a future focus being on cost-effective ways to standardize the capture, coding, storage and sharing of aggregated data captured by GPs.
6. PHNs want to be able to download raw data from the Portal for further manipulation and analysis. Given some data may be restricted, we also recommend the inclusion of interactive visualisations, to allow further manipulation and analysis.
7. As well as quantitative data PHNs suggested the Portal could contain qualitative data. This could be in the form of testimonials or "My Story" type experiences, although this data is unstructured it is delivering invaluable insights of examples from within communities. The transference of individual data sets containing text, voice and video data is recommended for later phase of the Portal, however, the recommendation at this point is to investigate the potential sources, further benefits, and collection strategies.
8. Make it easy to find what data is available, a catalogue of data that is stored on the Portal, details of collection, roadmap of additional data sources, update frequency and origin of source data should be minimum requirements. Informing users of changes should be delivered as changes and updates occur.
9. Develop a Community of Practice and/or consultancy service, to enable more sharing of ideas and information. This could incorporate a range of data and analytics experts, to help in analysing and interpreting data, results, and conclusions.
10. We recommend a section of the Portal be made available to hold research papers and latest research findings in suicide prevention data and strategies and other material identified as beneficial to the PHN community. Or as a minimum, direct to other suicide prevention research and implementation portals.

3. Introduction and Background

3.1. The National Suicide and Self-Harm Monitoring Project

The System was announced as part of the Prioritising Mental Health Package in the 2019-20 Australian Government Budget. The AIHW is managing the three-year Project, which is responsible for building the System. The Department of Health is funding the AIHW \$5 million per year, for the three years (2019-20 – 2021-22) to develop and implement the system. As part of the Australian Government's commitment to mental health and suicide prevention through the 2021-22 Budget, the Suicide and Self-harm Monitoring System will continue to develop and expand, with additional funding of \$4.2 million per year from 2022-23 to 2024-25.

The AIHW is working closely with the National Mental Health Commission which has established an Expert Advisory Group, made up of lived experience representatives, government representatives, researchers, and other professionals from the suicide prevention sector, to provide advice as required for the development and implementation of the System.

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, which includes a commitment to improving the quality and timeliness of national data on suicide and self-harm.

Improved national surveillance and data will inform mental health and suicide prevention policy makers, service providers, communities, and researchers to identify emerging areas of concern and population sub-groups. 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.

The Project has two broad objectives:

- To build an integrated data system which will help increase the timeliness, coherence, and quality of data on suicide, suicide attempts and self-harm.
- To undertake specific data development activities to improve data collection and supply pertaining to suicide, suicide attempts and self-harm.

These two objectives are being addressed concurrently during the Project. The first objective is being addressed through the development of the System in two phases of project activity.

Phase 1 was the development of the Monitoring website which presents national morbidity and mortality data sources and is intended for public users, this 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 Portal which aims to hold additional data sources for specialist users with restricted access and will become available over time (2021-2022), with a pilot in place by the end of 2021.

This report focuses on the data required for the Portal and development activities, to improve the timeliness and quality of sourced data and the potential incorporation of additional data sets. For example, over time additional data sets may be included such as police incident data, emergency department data and health service data. This will allow for a comprehensive and timely picture of the rates of suicide and self-harm.

3.2. The Journey So Far

AIHW were tasked with building a system for National Suicide & Self-harm Monitoring. This development has two main phases:

Phase One – a public monitoring website, which has been on-line since September 2020. This currently consists of the following data sources:

- National Mortality Database (NMD)
- National Hospital Morbidity Database (NHMD)
- National Ambulance Surveillance System (NASS)
- Multi-Agency Data Integration Project (MADIP)
- Australian Defence Force (ADF) Suicide Data Sources
- Australian Burden of Disease Study (ABDS)
- Jurisdictional coronial data

These sources, in turn, provide several reports and statistics including:

- Deaths by suicide in Australia, over time and by gender, age, state, Indigenous status and levels of geography
- Ambulance attendances – suicide and self-harm behaviours
- Intentional self-harm hospitalisations

For a complete view of the data sources available the link to the AIHW website data sources is:

<https://www.aihw.gov.au/suicide-self-harm-monitoring/data/technical-notes/data-sources> Although the data is at a high-level, the awareness of the Portal and subsequent adoption and usage has been increasing.

The Centre for Mental Health Melbourne School of Population and Global Health University of Melbourne published a report in March 2021 - *Evaluation of the National Suicide and Self-harm Monitoring Project and System| Interim Report* which provides an overview of evaluation activity conducted between May 2020 and March 2021. The report includes some preliminary findings, mainly related to the development and publishing of the monitoring website.

Phase Two – At the time of consultation the AIHW had engaged web developers to deliver the Portal. A minimal viable product with two factor authentication has been established and is currently undergoing Beta testing. The Portal is planned to be available for use by 2021.

The Portal will allow users to login to access confidentialised aggregate data that are not currently available on the website. The information provided on the portal will enable policy makers and service providers to identify trends in the data or emerging areas of concern in relation to suicide and self-harm and will in turn support policy decisions and planning of suicide prevention activities.

The site will include national morbidity, mortality and ambulance attendance data. States and territories may choose to contribute other data to the system (such as suicide register or police data); however, the AIHW will control the inclusion of all data on the site to reduce the risk of privacy breaches. The AIHW is working with data custodians and users in government and PHNs to determine:

- What data should be made available within the Portal;
- How data should ingress to the Portal;
- What analyses should be performed within the Portal;
- Who should be permitted restricted access to data and analyses within the Portal.

The AIHW has commenced workshops with states and territories, beginning with the ACT in March 2021

The ACT Portal workshop provided valuable insights and understandings of the ACT's approach to the Portal. Participants of this workshop were from relevant ACT organisations involved in suicide prevention and service planning, including Office of Mental Health and Wellbeing (ACT Government), Capital Health Network (ACT Primary Health Network), ACT Coroner's court, ACT Health Directorate and Australian Federal Police. This workshop introduced the concepts and vision for the Portal among participants, and workshopped participant ideas what data and how they would use the Portal in their service planning and suicide prevention activities. Themes from participant feedback included data on risk factors leading up to a suicide, geocoded data at a finer level, and providing the tools and excel documents to be able to manipulate data themselves. Governance structures for the Portal were also discussed.

3.3. Objective of this Report

The objective of this report is to detail the preferences PHNs gave for the Portal as captured across a range of collaborative workshops and meetings between AIHW, PHNs, Black Dog and the SAS Institute. The aim is to provide detailed feedback of both the existing use of data across the PHN community, the key challenges PHNs face when accessing and using data (generally, not just in relation to the Website), as well as the key future state requirements for a more detailed and accurate repository of data to support on-going initiatives aligned to self-harm and suicide prevention.

The report details the specific data requirements highlighted by workshop participants and aims to justify why such data will be beneficial to PHNs. A high-level view of the prioritisation of such data sets is given but, this will

require further effort to reach an agreed prioritised list of such data assets. This report gives the justification for which data is proposed as being pivotal towards the next phase of the National Suicide and Self-harm Monitoring Project.

3.4. Approach

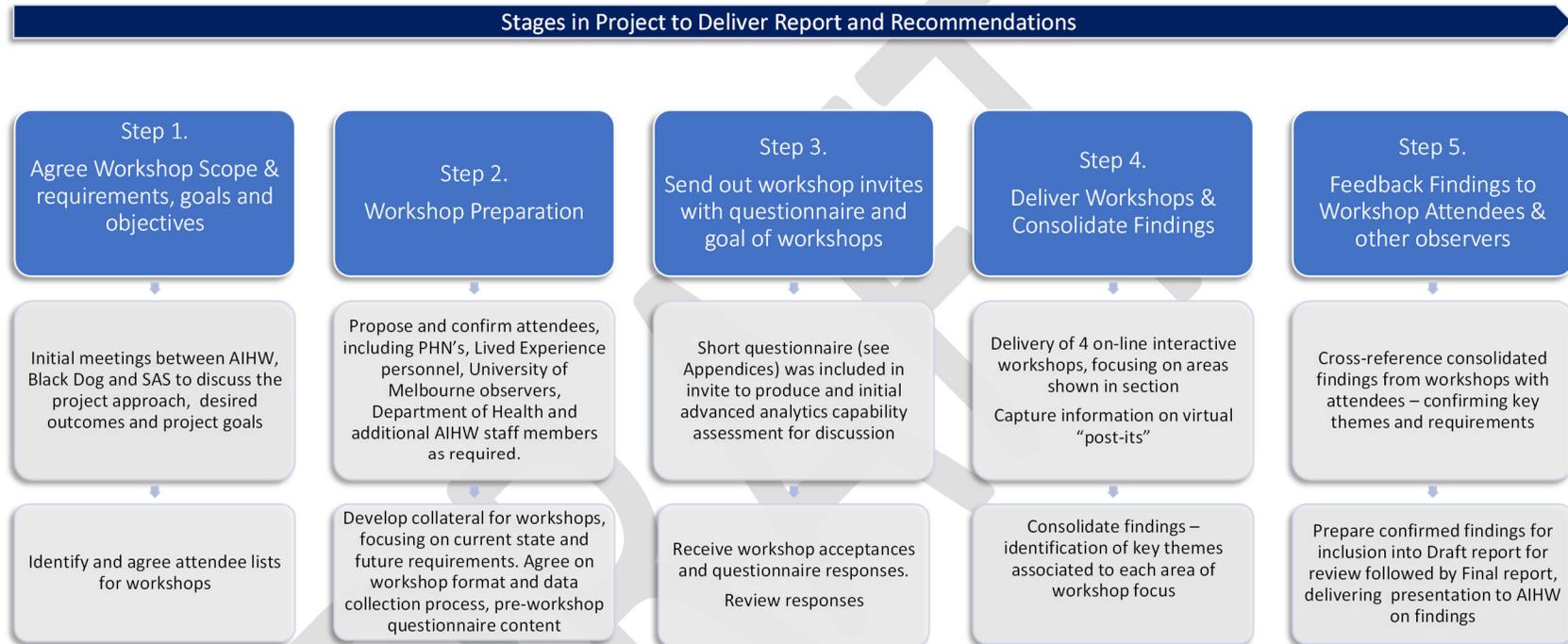
Black Dog and SAS were asked to deliver a collaborative project for AIHW with the focus on identifying and prioritising key requirements for the Portal. The Portal is an integrated data platform aiming to increase the timeliness and availability of national suicide and self-harm data. The Portal will provide an evidence-base for governments and services, such as PHNs to better respond and target suicide intervention and prevention activities through:

- Understanding of imminent risk, including hotspots and clusters
- Understanding of risk and protective factors
- Development and ongoing reporting of the evidence base for suicide prevention among high-risk populations where possible.
- Improved access to suicide prevention data and information.

The overall project approach can be summarised in Figure 2 on the following page:



Figure 2: Project Approach



There are five key stages in the project as described above. Core to the success of the project is the ability to collect information and preferences for the Portal from appropriate sources. Several consultative workshops were held, with the purpose of understanding the preferences of PHNs in terms of data accessibility and their intended use of the Portal, and the feasibility in allowing secure sharing of suicide and self-harm data between agencies.

The PHNs are key in the 'preferences gathering' phase, with 12 of the 31 PHNs participating in the National Suicide Prevention Trial (NSPT), funded by the Commonwealth Department of Health. Black Dog Institute is also commissioned by the Commonwealth, to provide suicide prevention research, implementation, and data support across the 12 NSPT trial sites. This has included the provision of suicide data analysis reports to PHNs where possible, utilising SA2 level NCIS data, geospatially mapped to identify suicide 'hotspots', 'at risk' cohorts and suicide means information, to support PHN suicide prevention planning and service commissioning. Subsequently, the PHNs consulted in this project are in a good position to contribute, with valuable learnings from the NSPT including the application of data in suicide prevention activity.

3.4.1. Workshops

Attendees:

There were approximately 40 attendees representing twelve PHNs across four workshops, held in 'virtual' mode using Zoom facilities on the 8th, 9th, 13th, and 20th July 2021, overall, the following organisations were represented:

- **PHNs** – represented by North Coast, North-West Melbourne, Western NSW, Brisbane North, Country South Australia, South-Eastern NSW, Northern Territory, Tasmania, Western Australia and Central Queensland, Wide Bay and Sunshine Coast
- **National Mental Health Commission** - Lived Experience Representatives
- **Kimberley Aboriginal Medical Services (KAMS)** - part of the NSPT working in partnership with WA Primary Health Alliance during the trial
- **The Oasis, Townsville** – ex-ADF Community Centre – part of the NSPT, working in partnership with Northern Queensland PHN
- **Department of Health** – Project Observers
- **University of Melbourne** – Project Observers
- **Australia Institute of Health and Welfare** – Project Sponsors and observers

Additionally, the Project Team from Black Dog Institute (BDI) and SAS were represented at all workshops.

A full list of all attendees by workshop, including their organisation and their role can be found in Appendix B.3

Workshop Format

- Each of the workshops were of one hour duration, each one being recorded. Welcome and Introduction (5 minutes).

Attendees were invited to introduce themselves through the Zoom chat facility. The three main goals of the session were explained to attendees, namely:

- Introduction to the Self-Harm and Suicide Data Monitoring System. What is the Portal and why might it be useful to PHNs?
- Understanding the current use of data in PHNs in your suicide prevention work Understand how data is currently used and any limitations or challenges.
- Understanding what PHNs want to find out more of, regarding their regional suicide profile. What data and other assets would be beneficial and how can these assets support and inform improved planning, and enable the implementation of suicide prevention strategies?
- Introduction to the State and Territory Information Portal (5 minutes)

A short introduction for delegates covering the following:

- A brief introduction to the monitoring system
- A brief description of Public Facing Monitoring site
- High-level description of the intent of the Portal
- Outline the future vision for the monitoring system and ensuing benefits to PHNs
- Understand *current state* of PHN suicide prevention initiatives (10 minutes)

Workshop attendees were divided into "breakout rooms", typically 3 or 4, each breakout rooms consisting of between 3 to 5 attendees representing PHNs, as well as various observers and facilitators from BDI and SAS. Within a breakout room, a virtual white board was available, allowing attendees to post concise but specific responses to questions or topics of conversation. The following questions were utilised to drive conversation and encourage comments and participation from the attendees:

- What data sources do you currently use to inform the setting of suicide prevention strategies and plans?
- How does the data help you make decisions about suicide prevention strategy and activities? (State three ways)
- What are some current challenges related to data for suicide prevention?
- What steps are involved to turn raw data into a suicide prevention strategy and plan?

Driving discussion around the four questions, the project team's aim was to gain an understanding of what the PHNs currently utilise data assets for, to support suicide prevention initiatives.

- Feedback from current state breakout rooms (10 minutes).

Each facilitator fed back to the whole group the key outputs from their breakout group.

- Assess future needs of PHNs for suicide prevention activities (15 minutes).

Returning to the same breakout rooms as those allocated for the review of the current state, attendees focused on likely future preferences and the rationale for such needs. The following questions were utilised, to further drive conversation and encourage comments and participation from the attendees:

- What new data sources would enable you to better plan suicide prevention activities?
- What new insights/trends/information would you like to see made available?
- How would this new data inform your regional suicide prevention planning?
- What priority-population and risk factors do you want to analyse, but currently cannot?
- How would you like data to be presented/analysed on the AIHW Portal to make it useful?
- How might you use and share the data from the AIHW Portal?

From driving discussion around the six questions, the project team's aim was to gain an understanding of what the PHNs would like to see available and why this information would be useful to them.

- Feedback for future state from each of the breakout rooms (10 minutes).

Each facilitator fed back to the whole group the key outputs from their breakout group relating to future requirements.

- Workshop Closure and describe next steps.

Each workshop was closed by thanking all the attendees and describing next steps, these being:

- For BDI and SAS to consolidate all workshop findings.
- Separate sessions for the project team to feedback consolidated workshop findings, ask further clarification questions, and to field questions from session attendees from both Lived Experience and PHN attendees.

3.5. Role of Primary Health Networks in Suicide Prevention

PHNs were established in 2015 with the key objectives of increasing the efficiency and effectiveness of medical services for patients, particularly those at risk of poor health outcomes, and improving coordination of care for patients². Operational and flexible funds are allocated to the PHN by the Federal Government. This includes a portfolio and flexible funding pool for Mental Health Care which includes suicide prevention. All PHNs are required to support a systems-based regional approach to suicide prevention, in partnership with the Local Health Networks and other key stakeholders³.

The role of PHNs broadly is to:

1. Understand the health care needs of their community through needs assessment, analysis, and planning. This includes mapping existing services, identifying service gaps, and ensuring value for money.
2. Provide support to GPs to be safe, high quality, use evidence and research and eHealth systems. Reduce numbers of patients attending emergency or being admitted where it could be managed in the community.
3. Commission health and medical/clinical services for local groups most in need.

In 2019, guidelines were given to PHNs on their remit for suicide prevention:

1. Plan for integrated, systems-based suicide prevention activity including creating a joint regional mental health and suicide prevention plan with their Local Health Network.
2. Commission community-based suicide prevention activities based on priorities emerging from regional planning and needs assessment processes. This includes a particular focus on commissioning services for Aboriginal and Torres Strait Islander people and commissioning of follow-up services for those who have self-harmed or had a suicide attempt (Aftercare).

Additionally, in 2016, the Commonwealth Department of Health launched the National Suicide Prevention Trial. This initiative was focused on trialling systems approaches to suicide prevention in 12 regions across Australia, with the objective of reducing suicide attempts and deaths. For the past five years, these 12 PHNs and their communities have been supported by the Black Dog Institute to design and deliver best practice suicide prevention initiatives, tailored to the needs of their communities. In the 2021-22 Budget, the 12 PHNs were each allocated \$1m for the continuation of suicide prevention strategies and activity.

²<https://www.health.gov.au/initiatives-and-programs/phn/what-phns-do>

³<https://www.health.gov.au/resources/publications/joint-regional-planning-for-integrated-mental-health-and-suicide-prevention-services>

There is a broader political context for suicide prevention funding and activity in Australia, with Ms Christine Morgan, first National Suicide Prevention Adviser, publishing her final advice to the Prime Minister in April 2021⁴. Although not exclusively PHNs, they would have taken a keen interest in the findings given this will likely impact future Federal funding. *Data and evidence to drive outcomes* was one of the four key enablers, alongside, the whole of government approach, lived experience knowledge and workforce and community capability. The recommended key shift in the report connected to data and evidence was *targeting groups that are disproportionately affected by suicide*.

The role and responsibility of PHNs in relation to suicide prevention will continue to evolve over the next few years. Given the government's focus on understanding community needs using data and PHNs central role within the health system; increasing their access to accurate, timely self-harm and suicide prevention data will be essential.

3.6. National Suicide Prevention Trial Context

The National Suicide Prevention Trial (NSPT) was part of Australia's growing commitment to trialling systems approaches to suicide prevention. The Black Dog Institute was funded by the Commonwealth Government and invited to support the twelve trial sites in recognition of our unique expertise gained through the significant systems-approach suicide prevention research trial, LifeSpan. The 12 sites that were part of the NSPT were:

1. Brisbane North PHN
2. Central Queensland, Wide Bay, Sunshine Coast PHN
3. Country South Australia PHN
4. Darwin (Northern Territory PHN)
5. Kimberley (Western Australia PHA)
6. Midwest (Western Australia PHA)
7. North Coast NSW PHN
8. North-Western Melbourne PHN
9. Northern Queensland PHN
10. Perth South (Western Australia PHA)
11. Tasmania PHN
12. Western NSW PHN



⁴ <https://www.health.gov.au/sites/default/files/documents/2021/04/national-suicide-prevention-adviser-final-advice-executive-summary.pdf>

Each trial site served a priority population within their region that had been identified as being at increased risk of suicide, based on a local analysis of needs. The priority populations each trial site focussed on are specified in Table 1.

Table 1: Priority Populations by Trial Sites

Priority Population	National Suicide Prevention Trial Sites
Aboriginal & Torres Strait Islander People	Brisbane North; Central Queensland, Wide Bay; Sunshine Coast; Western NSW; Country SA, Darwin (particular focus on youth), Mid-West WA; Kimberley; North Coast NSW
LGBTQIA+	Brisbane North, North Western Melbourne
Ex-ADF personnel and their families	Townsville, North Queensland
Men	Brisbane North (aged 25-54); Central Queensland, Wide Bay, Sunshine Coast (aged 25-54); Western NSW (age 25-54 in farming and mining); Tasmania (age 40-64); Country SA (25-54); North Coast NSW (40-69)
Older people	Tasmania (male and female 65+)
Youth (aged 16-25)	Country SA; Perth South; Brisbane North
Rural and remote	Mid-West WA (farmers, fishers, and FIFO workers); North-Coast NSW (focus on farmers in Bellingen)

4. Current State View

4.1. Data Assets currently utilised

Table B.1 shows usage of currently accessed data sources by each of the PHNs involved in the workshops. The main observations are:

- There are a wide range of data sources utilised by PHNs. There is a relationship between more populous PHNs, and the number of data sources utilised. For example, the Northern Territory, Western Australia, and Tasmania utilise fewer sources, while SE New South Wales utilise the most.
- Of the 10 PHNs who attended the workshops and 2 organisations connected to the NSPT, 9 stated they currently accessed the AIHW publicly available data (the Public Site), the exceptions being North Coast NSW and Kimberley Aboriginal Medical Service.
- Somewhat surprisingly, less than half of the PHNs stated they used ABS data (this maybe not realising that certain data sources are in fact sourced from the ABS) Data sourced from hospital admissions, including Emergency Department data was utilised by just 4 of the PHNs, these being Country South Australia, SE NSW, Tasmania, and Central Queensland.
- Police data was said to be utilised by only 3 of the PHNs, these being Western NSW, SE NSW, and Central Qld.
- Specific Research and Evaluation data is only utilised by 2 PHNs, these being two of the most populous PHNs, SE NSW and NW Melbourne.
- NCIS or locally specific coronial registry data usage is also prevalent. Examples include the Queensland Suicide Registry and the Victorian Coroner Data.
- Several PHNs are actively utilising what is known as “unstructured” data, this comes in the form of data taken from the following situations:
 - Discussions with community-based working parties, stakeholders, and consultation groups
 - Anecdotal discussions with Lived Experience representatives
 - Other “on-the-ground” discussions
- There are also a range of other data sources that PHNs utilise, these include:
 - AISRAP (Australian Institute for Suicide Research and Prevention) used by Brisbane North
 - PHIDU (Public Health Information Development Unit) used by Northern Territory
 - Black Dog Institute Suicide Data Analysis Reports used by SE NSW and North Coast NSW
 - Local and State specific health related data sources, for example, NSW Health Statistics and Tasmania Health)

-
- The availability and usage of data sources is variable across the PHNs partaking in this project. Although sources that cover national level information (ABS and AIHW) are the most prominently used sources, there are also a range of specific and focused geographically appropriate sources utilised by PHNs. These range from local and state-based sources, academic and research institutions and emergency services related data.

DRAFT

4.2. How is Data currently utilised?

The workshops highlighted three main uses of the data currently available. These are for:

1. Planning purposes
2. Location based analyses
3. Impact & Measurement reporting

Table 2 below, shows examples within the three core areas of activity.

Table 2: Current data sources utilised by PHNs.

How is data currently utilised?					
Examples					
1. Planning	Needs Assessment & provision of new services	To inform and input to prevention strategies	Knowledge about service availability, where to implement new services	Capacity building in particular services health and non-health	Ability to partner with other key organisations
2. Location & Targeting	Localised response that speaks to community needs	Shapes and informs conversations with stakeholders	Target Groups & Regions	Identify high risk locations & groups	
3. Impact & Measurement	Measure effectiveness of previous investment / impact	See whether new services / interventions are making a difference	Assess reach of suicide prevention activity across region	To inform decisions	

Data is used primarily for three main reasons, these being:

- Planning and strategy – using data to understand the extent of the suicide and self-harm in their region, this is then aligned to existing services and strategies in place and allows planning and assessment to be tuned accordingly.

-
- Location and targeting – based on data and appropriate analyses, PHNs are able to focus on specific areas and regions where high-risk groups are prevalent, allowing for more focused support and prevention initiatives to be applied.
 - Assessing and measuring effectiveness of initiatives – based on on-going data collection and assessment, this application “closes the loop” in terms of measuring the impact of suicide prevention initiatives. On-going data collection and timely updates, when possible, allows for assessing the outcomes of investment in programs.

4.3. Significant Challenges

During the workshops, the attendees were asked to comment on any specific challenges they encountered when trying to access or use data, across all possible sources.

It became evident there were several common themes that are associated to accessing and utilising data to support the range of activities as specified on page 28.

- Accessibility and Timeliness: These were common concerns from the PHNs. Associated to these challenges is the need to know and understand where (and what’s available) to look for certain key points of information. Attendees believed a more detailed register or catalogue of data sources would be useful a view as to the schema identifying data sets and their sources and potential linkages as they develop.

There was also concern in terms of having access of limited access to specific data sets, for example, Brisbane North PHN, were only permitted limited access to Queensland’s Suicide Registry.

Timeliness was a consistent issue, this manifested itself in two forms:

- i. Updates of longer-term data
- ii. “Real-time” or “live” data updates

For longer-term data there were issues around having to endure a time-lag of 2-3 years for updates to data (Central Queensland and WA). This aspect of timeliness relates to the feeling that “data is out-of-date by the time we receive it”. NW Melbourne cited delays in receiving coroner data as a challenge.

For “real-time” data there is the definition of what constitutes real-time? Is it even “real-time”, or is it “near real-time”? or something else? The concept of “real-time” appeared to be associated to the requirements of receiving feeds of data from the emergency services (police and ambulance) automatically (or as soon as is possible post an incident), this was in some cases termed as a “live” data feed.

- Reliability: Several issues concerning the reliability (and consistency) of data were discussed during the workshops. These issues covered inconsistencies between data sources (Country SA) and across time periods (SE NSW). Missing data was also stated as an issue. However, some of the missing data problems are simply down to too fine a level of geographic analyses is required, which in turn leads to

small counts or observations in such areas. This is linked to the requirement to drill-down into data and review at a low-level of granularity (see following point).

- Granularity: a consistent theme from workshop attendees was the need to “drill-down” into finer more granular levels of geography or remote and rural areas. The issue cited by many PHNs was that small numbers of cases or incidents were observed, hampering statistically reliable reporting. This is a function of low numbers of self-harm and suicide attempts, which of course, is a positive thing, so the inability to perform limited, small geography analysis is in fact a positive outcome of improving prevention. The second area where greater granularity was requested by PHNs was understanding the demographic characteristics of those that have attempted or died by suicide, to improve the knowledge of at-risk groups.
- Lack of specific data sources was cited by many attendees as a drawback in achieving a better understanding of self-harm and suicide. Many of these challenges aligned to specific data requirements will be the focus of future state requirements, see page 31 Preferences for the Future . However, as a summary, not having access to the following specific data sources was a challenge:
 - **Aftercare referrals and service utilisation** – giving the ability to monitor on-going progress and use of services
 - **Case closure** information – giving the ability to track case closure rates and the effectiveness of intervention. The need to understand how an individual is progressing 28-days following discharge from hospital for example would be beneficial to understand
 - **Improved access to suicide attempts and incidents** (and ability to differentiate between attempts and drug overdoses); data from GPs which identifies suicide ideation and self-harm
 - **Crime-statistics** containing self-harm reporting
 - **Police data** (SE NSW), Queensland Health ambulance data (Brisbane North).
 - **Small population regional and rural data sources** (this issue is linked to reliability of data and the often relatively small counts of incidents observed)
- Additional data related challenges observed from workshops, include:
 - Missed opportunities for collecting data – due to levels of engagement within communities, there are many opportunities or touchpoints to engage and listen to individuals and capture conversations and critical insights. This often-anecdotal evidence is extremely valuable and relates to real-life information and experiences which would be valuable to share (across PHNs).
 - Different services not sharing data, or and lack of communication with each other regarding suicide ideation.
 - Varying levels of data literacy within PHNs.

5. Preferences for the Future

5.1. Future Data Preferences

A primary focus of the workshops was to assess the future suicide prevention needs of PHNs, particularly in data, so that the Portal can be developed to meet these needs. This information on the PHN future needs was collected in the second breakout sessions in each workshop and have been summarised collectively in the following subsections.

5.1.1. Desired Data Sources

Workshop attendees were asked to discuss which data sources would enable them to better understand self-harm and suicide in their region.

A variety of responses were received, consolidated, and thematically analysed. The themes are shown as a word cloud in Figure 3. There was no limit on the number of themes to ensure that as many responses as possible were classified. Some responses fell into more than one theme (e.g., "hospital admission data of those presenting with suicide ideation" falls into both 'Hospital admission' and 'Suicidality' themes).

Six key themes, with some specific needs were identified from the responses, are listed in Table 3.

Figure 3: Word cloud illustrating the type of suicide data or data sources PHNs would like to have. The size of the words represents the frequency of occurrence.

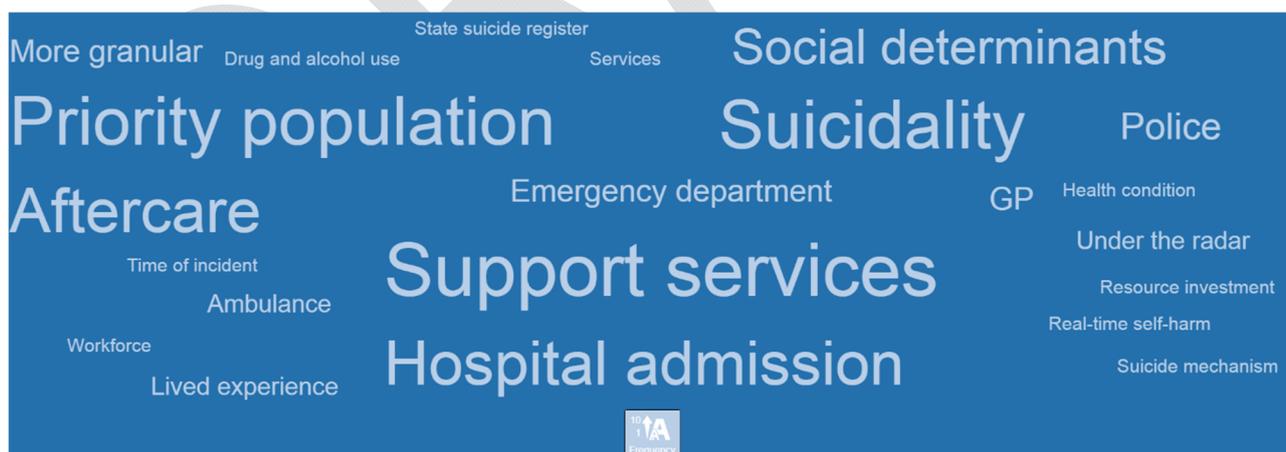


Table 3: Six key themes identified from the thematic analysis of PHN data/source needs responses. Some specific needs which fall into multiple themes are only presented in a single key theme.

Key Themes	Data sources PHNs would like access to:
Aftercare	<ul style="list-style-type: none"> • Data from on-going monitoring of post-attempt activities. • Referrals to and utilisation of aftercare support services. • Follow-up from both emergency department (ED) presentations and hospital admissions.
Hospital admissions	<ul style="list-style-type: none"> • Data from Intensive Care Unit. • Admissions data of those who have had a suicide attempt • Data on people who present to Emergency Departments but are not admitted.
Priority population	<ul style="list-style-type: none"> • Data about at-risk people from service providers. • Local-level data (including means) on veterans. • Aboriginal and Torres Strait Islander people. • People who do not engage in services (i.e., they are 'under the radar').
Social determinants	<ul style="list-style-type: none"> • Data on people experiencing homelessness, disability, violence (domestic/family), socio-economical advantage/disadvantage from relevant agencies.
Suicidality	<ul style="list-style-type: none"> • Data distinguishing between those who are self-harming with and without the intent to die by suicide. • Suicide death, attempt, and ideation data from community, community service providers, allied health providers, and crisis lines (geospatially mapped). • More frequent national survey of mental health and wellbeing.
Support services	<ul style="list-style-type: none"> • Data from forensic health, youth justice and victim support services. • Data from support services in remote/rural locations. • Self-harm data broken down to service provider-level.

5.1.2. Desirable Insights, Priority Populations, and Risk Factors

Following the identification of desired data, PHNs were asked the following question to assess what insights, trends, and information they would like to know, without being restrained by technical boundaries (i.e., 'blue-sky' thinking):

"What new insights/trends/information would you like"?

Responding to this question provided the opportunity for PHNs to share how the new data sources would enable them to better understand the trends or patterns within their local community. Thematic analysis was

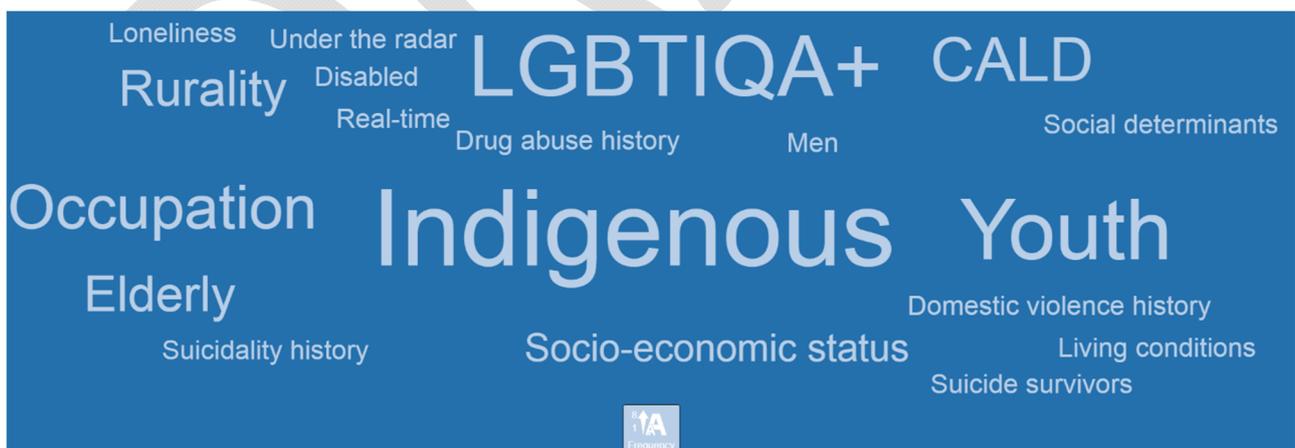
Key themes	Specific Needs
	<ul style="list-style-type: none"> Levels of engagement with services prior to suicide/attempt. Identifying services that have worked.
Social determinants	<ul style="list-style-type: none"> Looking at the living conditions (e.g., homelessness, violence) of those who have attempted or died by suicide. Linking social determinants of suicide. Looking at the impact of loneliness, social isolation, and disconnectedness.

After assessing the broader data and trend/information needs, PHNs were prompted with the following question - "What priority-population and risk factors do you want to analyse, but currently cannot"?

As shown in the word cloud (Figure 5), the top five most desired priority populations or risk factor categories to analyse in more detail in the future are the Aboriginal and Torres Strait Islander, LGBTQIA+, youth, CALD populations, and occupation groups. Regarding insights on the Aboriginal and Torres Strait Islander populations, PHNs wanted more granular data and data on walkabout men (i.e., those men who have undergone the traditional transition into adulthood).

Regarding insights on the youth population, PHNs wanted to look at the impacts of COVID, targeted interventions, and sense of community. The occupation category in this analysis includes looking at fly-in-fly-out (FIFO) workers, miners, and farmers. The elderly population, particularly those in palliative care and residential homes, was also of interest to PHNs.

Figure 5: Word cloud illustrating the specific priority populations and risk factors that PHNs want to know about (the size of the words represents the frequency of occurrence).



5.1.3. Utility of New Data

After assessing the data needs, PHNs were asked how the new data will inform them in their suicide prevention planning, needs assessment and measurement. Thematic analysis was used to classify the responses, with the themes shown in the word cloud in Figure 6. Four key themes were identified and broken down into specific activities which will be supported by additional data (Table 5).

Figure 6: Word cloud illustrating what PHNs will use new data to inform in their suicide prevention strategy. The size of the words represents the frequency of occurrence

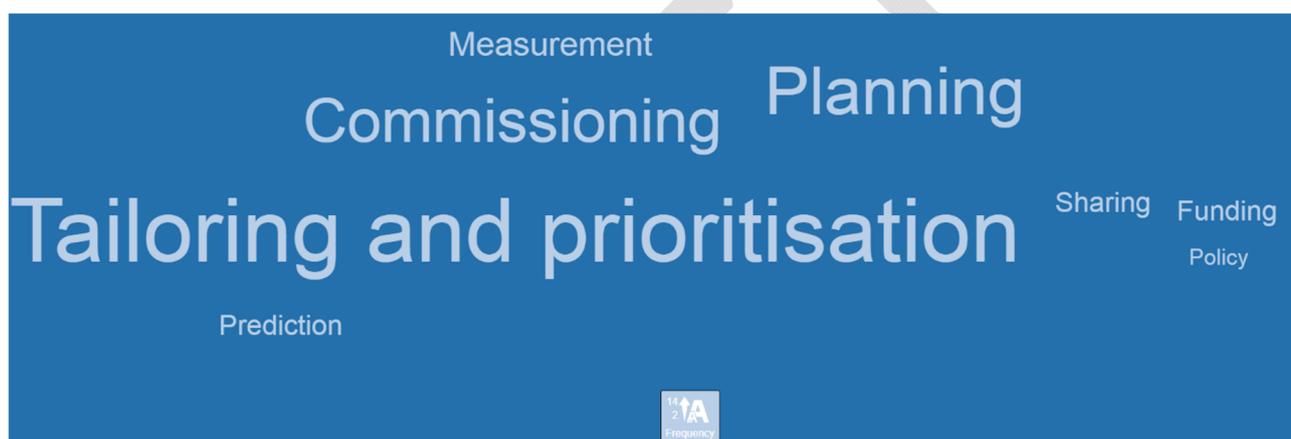


Table 5: Four key themes identified in the thematic analysis of what PHNs will use new data to inform (some specific uses which fall into multiple themes are only presented in a single key theme)

Key Themes	Specific Activities to Inform
Commissioning	<ul style="list-style-type: none"> • Adjusting and justifying the allocation of resources to priority groups and local regions. • Increasing service responsiveness to community need, particularly in postvention.
Planning	<ul style="list-style-type: none"> • Monitoring of emerging trends for activity and resource planning. • Providing evidence as a basis for community investment.
Tailoring and prioritisation	<ul style="list-style-type: none"> • Identifying gaps in services and needs. • Building capacity with gatekeeper and health professional training. • Tailoring services and programs to priority populations (e.g., health literacy education and cultural support worker for CALD population).

Key Themes	Specific Activities to Inform
Measurement	<ul style="list-style-type: none"> • Evaluate effectiveness of existing services and past interventions. • Evaluate efficacy of risk factors in predicting suicidal behaviour.

There were clear parallels between the discussion we had with PHNs about their current use of data and how PHNs stated they would utilize new data sources that they would like access to. Having more granular, timely data would enable PHNs to have a much greater ability to ensure their planning, tailoring, commissioning, and evaluation of their suicide prevention activity was informed by strong data and evidence and met the needs of their community.

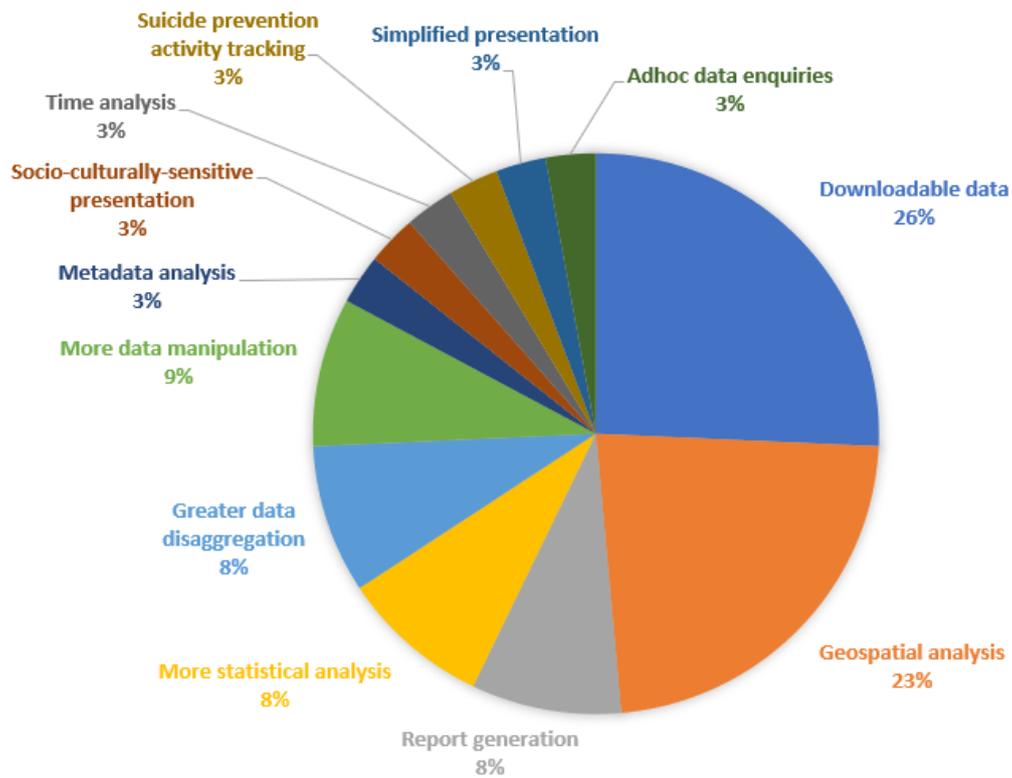
5.1.4. Delivery of New Data

One of the areas of enquiry within the workshops was how PHNs would like data to be presented within the Portal, to maximise its usefulness.

The following key preferences were stated (Figure 7):

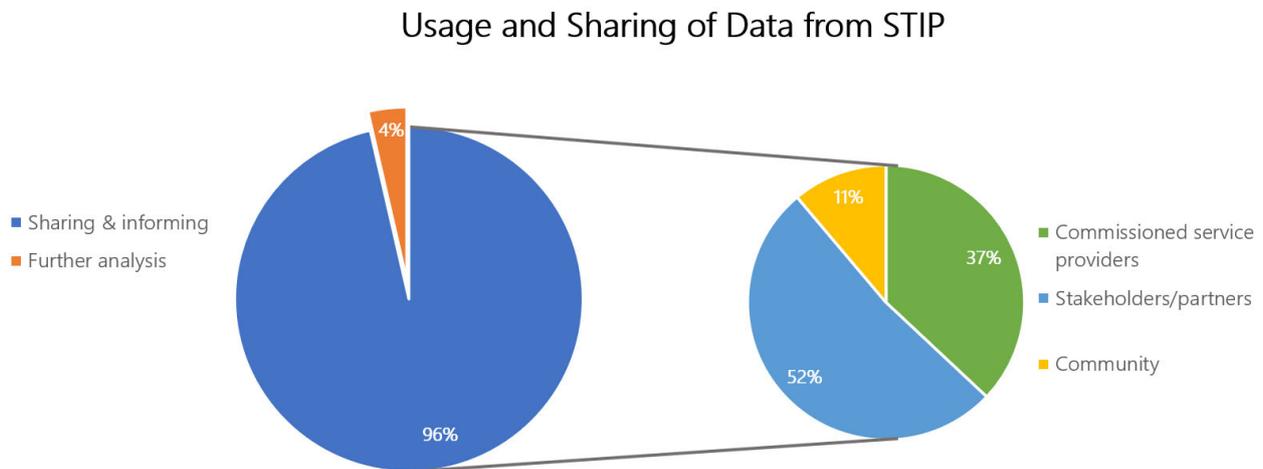
- Having the ability to self-serve data and assets from the Portal, and “slice-and-dice” and manipulate data to produce specific tabular, visualisations and mapping capabilities specific to individual PHN requirements
- Having the ability to download raw data for bespoke manipulation and further analysis and reporting
- Have flexibility to drill-down to a required (often fine) level of granularity
- Being able to extract data into a report format
- Having more advanced statistical analysis (e.g., the use of t-tests to test for significant differences between means)
- Being able to request data or analysis and ask questions about the data on an ad-hoc basis.

Figure 7: Pie chart showing percentage breakdown of the data presentation/analysis PHNs would like to see from the Portal.



The assessment of how PHNs want data to be presented and analysed aligns with how they want to share the data (Figure 8). Almost all (96%) of responses stated that they would like to be able to share insights from the data with other internal/external parties that play a role in suicide prevention. Portal user guidelines and permissions are being developed, which will allow strong data governance and permissions to be applied as appropriate. All PHNs, except for Primary Health Tasmania, stated they want to share data with external parties including key stakeholders, partners, and community members. Primary Health Tasmania stated they will share downloadable data internally with planning and evaluation teams, data analysts and epidemiologists.

Figure 8: Pie-of-pie chart illustrating the two desired usages of Portal data (sharing/informing and further analysis) mentioned by PHNs and which type of parties the data will be shared with.



5.2. Specific Differences by PHN

Given Australia is divided into 31 PHNs there are clearly significant differences in the size, population density and regional context of each PHN. All these factors influence the availability and usefulness of self-harm and suicide prevention data. However, as outlined in section 3.5, all PHNs have the same remit for suicide prevention as outlined by the Commonwealth Government. The following sections highlights the areas where the geography and demography of the PHN impacts their desire for access to different types of data.

5.2.1. Demography

As part of the NSPT there were a mix of urban, rural, and blended PHNs.

The Western Australia Primary Health Alliance (WAPHA) was split into three regions – Perth South, Mid-West, and Kimberley.

Primarily Urban	Urban & Rural Areas	Primarily Rural & Remote
North-West Melbourne	South-Eastern NSW*	Kimberley (WAPHA)
Brisbane North	Central Queensland, Wide-Bay, Sunshine Coast	Western NSW
Perth South (WAPHA)	Primary Health Tasmania	Mid-Coast (WAPHA)
	North Coast NSW	Country South Australia
		Northern Territory

Primarily Urban	Urban & Rural Areas	Primarily Rural & Remote
	The Oasis (in Northern Queensland)	

*Part of the LifeSpan trial and opted to attend the workshop. All other attendees were part of the NSPT.

Key data insights related to rurality

- **Geographic granularity of data** – Many PHNs have very low population density and relatively small numbers of incidents, however, given the small, connected communities, the suicide deaths often have a significant impact on the community. This creates challenges as the incidents are then aggregated at SA3 level to protect confidentiality (WAPHA).
- **Data Accuracy** – Fly in, Fly Out (FIFO) or drive in, drive out workers are not counted in the data due to their registered address and place of residence being in an urban area (Western NSW).
- **Access to Data Sources** - Suicide attempts are attended to by the police rather than ambulance services. Western NSW estimated that 90% of suicide attempts were attended to by the police.
- **Missing Data** – Given the size of the regions, people living rurally often have long distances to reach local hospital and therefore their suicide risk and mental health assessments are conducted over the phone. These people who are at risk are often missing from the data due to them not being admitted to hospital. In addition, many people do not attend hospital when experiencing suicidal distress, due to a lack of trust in the health system, so they are missing from the data (Western NSW).

Key data insights from priority populations

The 31 PHNs around the country have different representation of priority populations:

- **Indigenous populations** – Indigenous status is underreported in administrative datasets including the NCIS⁵ and hospital administrative datasets⁶. From the data available, we know the Indigenous rate of suicide ranges from 1.4-2.3 times that of non-Indigenous Australians⁷. The Kimberley region (WAPHA), Northern Territory PHN and Western NSW have a significantly higher proportion of Indigenous Australians. Indigenous communities would like sovereignty over their data and access to data on self-harm, suicide, service utilisation and acuity of risk to enable Aboriginal communities to self-determine and make data informed decisions (KAMS).

⁵ <https://www.ncis.org.au/wp-content/uploads/2019/11/Data-Statement-about-indigenous-identification.pdf>

⁶ <https://onlinelibrary.wiley.com/doi/full/10.5694/mja2.50401>

⁷ <https://www.aihw.gov.au/suicide-self-harm-monitoring/data/populations-age-groups/suicide-indigenous-australians>

- **LGBTQIA+** – The recording of gender identity and sexual orientation is a significant gap in administrative datasets, with sex [at birth] often being the only data point that is recorded. LGBTQIA+ Health Australia has worked with the ABS to standardise the collection and dissemination of data relating to gender, sex characteristics and sexual orientation⁸. Survey data shows LGBTQIA+ people have higher rates of suicidal thoughts and suicide attempts in Australia, than non-LGBTQIA+ people, but population level data are lacking. During the NSPT, North-West Melbourne PHN and Brisbane North PHN focused on LGBTQIA+ communities as a priority population⁹. Data on the rates of self-harm, suicide attempts and deaths in the LGBTQIA+ communities was highlighted in 50% of the discussions about which priority populations PHNs would like to better understand.
- **Veterans** – The locations of ADF bases; ex-serving men, women and their families are concentrated in a small number of PHNs. Brisbane North and Northern Queensland (Townsville) have the highest number of Department of Veteran Affairs clients (which includes Veterans and their families)¹⁰ in the country. The age-adjusted suicide rate among ex-serving men was significantly higher than in age-matched Australian men in 2013–2015 and 2015–2017¹¹. Veteran service providers would like more local data on the demographic characteristics of veterans to better understand and target services to their needs. Although the rates are higher, the numbers of ex-serving people dying by suicide are still relatively small. This means data can only be used for programs and interventions aimed at the whole veteran population. Layering and linking data on economic disparities, race, ethnicity and LGBTQIA+ status, social connection (including marital status and rurality), medical discharge, mental health, disability status and homelessness would create a much richer picture to implement prevention strategies and activity. The US National Veteran Suicide Data and Reporting Annual Report was highlighted as best practice¹² (The Oasis, within the Northern Queensland PHN).

5.2.2. PHN Organisational Differences

All 31 PHNs are operated by different Not-for-Profit organisations. The structure of each PHN differs, including the size and structure of the need's assessment (data analytics) and suicide prevention teams, and how much decision-making power they devolve to the organisations they commission to and partner with. The PHNs have varying levels of maturity in relation to their data, analytics, and systems-approach to suicide prevention. This

⁸ <https://www.lgbtiqhealth.org.au/new-australian-bureau-of-statistics-2020-standard>

⁹ <https://www.blackdoginstitute.org.au/news/targeted-suicide-prevention-for-lgbtqi-communities/>

¹⁰ https://www.dva.gov.au/sites/default/files/2021-07/lgas_mar2021.pdf

¹¹ <https://www.aihw.gov.au/suicide-self-harm-monitoring/data/populations-age-groups/australian-defence-force-suicide-monitoring>

¹² https://www.mentalhealth.va.gov/suicide_prevention/data.asp

will impact their desire for raw data versus data analytics, the variety of social determinants of suicide and related datasets they would like to analyse and access, and how much data they would like to share with their commissioned organisations.

5.3. Opportunities to Address Data and Analysis Needs

With the future needs of PHNs having been assessed, it is important to consider how to meet these needs and to identify opportunities.

Firstly, it is important to know what data attributes PHNs value - some of these have already been identified in the thematic analysis previously presented but were not formally addressed. From the ranking poll workshop activity, PHNs were asked to rank which data attribute they value, and which data attribute has been the most challenging to attain - the results are shown in Table 6. These attributes were based on the data quality, sensitivity, timeliness attributes from the Centres for Disease Control and Prevention (CDC) guidelines for evaluating public health surveillance systems¹³ and have been adjusted to meet the scope of this report.

Table 6: Ranking poll results on data attributes.

Questions	Ranked Attributes
What is most important to you in data? (based on 9 responses)	<ol style="list-style-type: none"> 1. Timeliness (close to real-time as possible) 2. Granularity (e.g., greater geospatial detail in data) 3. Accessibility (ability to attain data with minimal steps) 4. Sensitivity (ability to detect 'true' suicide rates) 5. Completeness (minimal missing data) 6. Cleanliness (ability to use data as is)
What is the greatest challenge you've had with data? (based on 11 responses)	<ol style="list-style-type: none"> 1. Timeliness (not close enough to real-time) 2. Granularity (lack of smaller details) 3. Accessibility (difficult to attain datasets) 4. Sensitivity (unable to detect 'true' suicide numbers) 5. Completeness (lots of missing data) 6. Cleanliness (requires additional cleaning before analysis)

¹³ <https://stacks.cdc.gov/view/cdc/13376>

The data attributes that PHNs prioritise align with what they've had the most challenge in attaining. Timeliness and granularity are the two most important and most challenging to attain attributes from the poll. This is also reflected in the desire for "real-time", "more granular", and "geospatial trend" data as shown in Figure 3 and Figure 4. Accessibility to data, ranked third in both questions and is reflected in the numerous data/source needs in section 5.1.1. Sensitivity is ranked fourth and refers to how 'true' the self-harm numbers are – this is dependent on the data collection methodology. For example, coronial suicide data is expected to be more sensitive than a "real-time" monitoring system that is based on suspected suicides due to the coronial investigation process filters out false positives and captures false negatives. Completeness and cleanliness rank last in the poll and are related to data quality. It is important to note that the ranking survey may not accurately reflect the data attribute priorities of PHNs collectively due to the relatively small number of responses. Nevertheless, the insights from the ranking poll and future state findings will be used to discuss improving maturity in data and analytics in the following sections.

5.3.1. Timeliness

Two key data timeliness needs were found from the workshop outputs:

1. Having real-time intentional self-harm, suicide, and suicide attempt data.
2. Knowing what time the self-harm incidents occur.

Real-time data is best obtained from sources that are first point of contact with those experiencing mental health distress, having attempted, or completed suicide. For suicide and attempt real-time data, this includes ambulance, Emergency Department (ED), and police as the data source. For mental health distress, this can include GP clinics and ambulance data again.

Ambulance service data is collected by paramedics, who are often the first and sometimes the only point of contact for acute mental health and self-harm events¹⁴. State and territory (excluding South Australia) ambulance service data is already being collated and coded through Turning Point (Monash University) for the development of the NASS. AIHW has already been using NASS self-harm data, receiving data on a monthly basis from January 2021¹⁵. Whilst it is ideal to receive more regular (e.g., fortnightly instead of monthly) ambulance self-harm data, this will be limited by the data cleaning and reviewing processes at Turning Point. ED presentations are another critical source of self-harm data as they capture people who are often missed in hospital admission datasets due to non-admissions. ED datasets are readily available in each state and territory¹⁶ but will require approval from the data custodians for access. Care should be taken when looking at intentional

¹⁴ <https://doi.org/10.1080/10903127.2017.1399181>

¹⁵ <https://www.aihw.gov.au/suicide-self-harm-monitoring/data/ambulance-attendances/ambulance-attendances-for-suicidal-behaviours>

¹⁶ <https://www.phrn.org.au/for-researchers/data-collections-available/>

self-harm ED cases as these are typically recorded by medical and clerical staff who may not have clinical coding training. Whilst ED is recommended as a real-time data source, additional recoding of ED diagnosis codes may be required as the diagnoses are not usually coded by trained clinical coders. In addition, Emergency Department data will not capture suicidal intent nor the complexities of mental health issues in intentional self-harm episodes, unless they are written in the clinical notes. State and territory police are another recommended source for real-time suicide data as they are often the first on scene in an incident; additional filtering of suspected suicides may be required. Some state police agencies are using structured forms (e.g., NSW police using Form P79A, QLD police using Form 1) to report deaths, including suspected suicides, making it quicker to review suspected suicide death cases and obtain close to real-time suicide numbers for reporting. Whilst these police forms are not yet standardized to create a coherent national police intentional self-harm dataset, it will be quicker to extract insights (e.g., using text mining algorithms) compared to free-text narrative reports, at least until a standardized method of recording new intentional self-harm cases is developed. Furthermore, some state police force has additional units within that focus on mental health crisis intervention (NSW Police Force Mental Health Intervention Team) or vulnerable persons, which may be a potential data source for real-time mental health crisis and intentional self-harm data. Some caveats of police reports include the incorrect recollection of decedent details obtained from the next-of-kin, who may be experiencing distress due to bereavement¹⁷. GP clinics may also serve as an initial point of contact for people experiencing mental health distress and often, but not always, record patient visits electronically, albeit in clinical notes.

Regarding the time of incidents, most of data sources record dates and times of presentations or death. In some suicides (e.g., suicides occurring in private residence with no other occupants), the body of the decedent may not be found immediately, which may obscure the time of death. Nevertheless, reporting of intentional self-harm, attempted, or completed suicides by time of day/week can provide priority time windows to implement suicide prevention activities (e.g., means restriction).

5.3.2. Granularity

PHNs have stated a desire for greater granularity in existing and future data, particularly for remote/rural areas and different service areas. Current public datasets report hospital admission and ED datasets record residents to SA2-level, as required for the National Minimum Dataset (NMDS)¹⁸. Other datasets or data sources, such as ambulance and police, do record incident or resident locations but may require geocoding to SA2-level. Despite the availability of some data at SA2-level (e.g., hospital admission, coronial), these have aggregated to SA3-level or higher (e.g., state-level or PHN-level) to preserve anonymity. It is recommended to present (geospatially or in tabular format) intentional self-harm, attempted, or completed suicide rates and numbers at an SA2-level, where possible. If aggregation is required to establish statistical confidence in rates (i.e., requiring suicide numbers >20), then it is recommended to aggregate by other variables (e.g., age-group, sex, year).

¹⁷ https://www.griffith.edu.au/data/assets/pdf_file/0035/1196855/QSR_Annual_Report_2020.pdf

¹⁸ <https://meteor.aihw.gov.au/content/index.phtml/itemId/344850>

5.3.3. Priority Populations

PHNs have expressed the desire to monitor numerous priority populations, including Aboriginal and Torres Strait Islander, LGBTQIA+ and CALD people, people with history of suicidality and/or having survived an attempt, youth, elderly, men, disabled people, veterans, and specific occupation groups such as miners, FIFO, and farmers.

Monitoring of these priority populations and associated emerging trends require consistent data collection and a minimum set of variables to identify the population. Whilst collection of Aboriginal and Torres Strait Islander mental health and intentional self-harm data has been improving in recent years (e.g., NMDS now making Indigenous status a mandatory dataset variable)¹⁹, significant under-representation is still expected²⁰. Data on the LGBTQIA+ population is not consistently collected as sexual orientation is not a mandatory variable in many state and national level datasets. Only two ABS datasets are known to have collected information on sexual orientation: the 2007 National Survey on Mental Health and the 2020 General Social Survey²¹. Successful linkage of the raw data from these two surveys with other health datasets will depend on whether identifying information is collected or not. Collection of the cultural and language diversity status, which may be used to identify people of the CALD population, in datasets requires a minimum of four dataset variables: birth country, language spoken at home other than English, English proficiency, and Indigenous status²². Currently, this minimum variable set is not required as part of the NMDS for health data; only the Indigenous status and sometimes the birth country is collected. Linkage of health data with data sources where the aforementioned four dataset variables for cultural and language diversity status might be recorded (e.g., Centrelink, Census data from ABS) would also enable identification of CALD people.

Youth, elderly, and men are readily identifiable from age/birth date and sex variables, which are mandatory as a NMDS in health data. Further insight into the youth population may be gained by collecting data from schools, particularly those with mental health programs²³. A desire to look at the elderly population in palliative care was raised in the workshop - palliative care is an interdisciplinary approach to improving quality of life for those with a terminal illness in which treatment is no longer viable²⁴. As such, it is recommended to access (and link) data

¹⁹ <https://meteor.aihw.gov.au/content/index.phtml/itemId/344846>

²⁰ https://www.atsispep.sis.uwa.edu.au/data/assets/pdf_file/0006/2947299/ATSISPEP-Report-Final-Web.pdf

²¹ <https://www.abs.gov.au/ausstats/abs@.nsf/Lookup/2007.0main+features62021>

²²

[https://www.abs.gov.au/ausstats/abs@.nsf/0/79fab04272992d54ca25697e0018febd/\\$FILE/ATT41EIH/DIMA%20Guide_Final.pdf](https://www.abs.gov.au/ausstats/abs@.nsf/0/79fab04272992d54ca25697e0018febd/$FILE/ATT41EIH/DIMA%20Guide_Final.pdf)

²³ <https://beyou.edu.au/resources/programs-directory>

²⁴ <https://palliativecare.org.au/what-is-palliative-care>

from the multiple institutes and services which may be involved, including hospitals, GP clinics, and residential aged care homes. Some palliative care datasets exist on the AIHW website²⁵ but these are primarily summary statistics – it may be beneficial to look at the raw data (and link to self-harm data) from which these statistics represent. To monitor people with a disability, the National Disability Insurance Agency (NDIA) will contain data (with NMDS²⁶) which can be linked with health or police data for greater insight in mental health and suicidality trends. Suicide monitoring of the veteran population is already being done by AIHW using linked Personnel Management Key Solution and National Death Index (PMKeyS–NDI) data²⁷. Further insights can be gained by increasing the granularity of the data to a local level. The PMKeyS–NDI is linked by address at time of incident variable²⁸, which can be mapped to a SA2-level variable. Aggregation by another variable (e.g., year, age group) may be necessary to obfuscate the relatively small numbers at the SA2 level.

People with history of suicidality, including suicide survivors, have not been well represented in state and national datasets. This may be in part be due to the fact that people with a history of suicidality can have multiple contact points including hospitals, police, postvention services, and community support groups. Linking data from these multiple contact points will provide not only a way to look at the journey of people with a history of suicidality but also monitor them for emerging trends.

Not a lot of insights into different occupation groups can be gained from hospital data as there are no mandatory occupation or employment status variables. Suicide data from the NCIS does contain an occupation text field, however it is not always completed or specific enough and often contains grammatical errors²⁹. Linking employment data from ABS's MADIP or Centrelink with hospital, police, and/or service data can provide insight into how many people in different occupation groups (e.g., FIFO, farmers, miners) experience mental health distress and suicidality. Further, if coding of occupation text fields is required, it is recommended to do so using the Australian and New Zealand Standard Classification of Occupations (ANZSCO).

5.3.4. Risk Factors

As with priority populations, PHNs have cited numerous risk factors they want to monitor. These include homelessness, living condition, family and domestic violence (F&DV) history, socio-economic status, social determinants, drug abuse history, and rurality/remoteness. Data on homelessness and living condition can be sourced from social service agencies such as Centrelink, where household information is collected. Additionally, the AIHW Validata platform contains homelessness data sourced from specialist homelessness agencies, which

²⁵ <https://www.aihw.gov.au/reports/palliative-care-services/palliative-care-services-in-australia/data?page=1>

²⁶ <https://meteor.aihw.gov.au/content/index.phtml/itemId/698074>

²⁷ <https://www.aihw.gov.au/reports/veterans/national-suicide-monitoring-adf-2020/data>

²⁸ <https://www.aihw.gov.au/about-our-data/our-data-collections/national-death-index/about-national-death-index>

²⁹ <https://www.ncis.org.au/wp-content/uploads/2020/07/NCIS-data-dictionary-version-4-2020.pdf>

can be used for linkage to intentional self-harm and coronial suicide data to look at the impact of homelessness. F&DV history can be obtained from police and ambulance data as they are often the first point of contact in F&DV incidents; the vulnerable persons unit may have relevant data for linkage. Another potential source of F&DV history is from child protection services, which have a NMDS³⁰. Socio-economic status is measured by the ABS using the Socio-Economic Indexes for Areas (SEIFA)³¹. A SEIFA value can be mapped to the SA2 where an intentional self-harm, attempted or completed suicide has taken place, providing insight into how the socio-economic status can affect intentional self-harm and suicide numbers. Suicide rates are higher in areas of low socio-economic status³². Education attainment and employment status are social determinants that AIHW is already monitoring. Other key social determinants of suicide include marital status, relationship conflict³³, incarceration history, and loneliness. Marital status is recorded by some data sources (e.g., NCIS) but is not mandatory in many health data sources (e.g., hospital admissions, and perinatal). Linking intentional self-harm hospital or police data to social service data (e.g., Centrelink) can identify the marital status of individuals in these datasets. Relationship conflicts (e.g., relationship breakdown) is more difficult to monitor as these may only be recorded in police reports as text from next-of-kin. Manual reviewing and coding of this text will be required when sourcing data from police. Incarceration history may be obtained from linking data from state justice departments with other intentional self-harm data (e.g., hospital admission or coronial). Insight into drug abuse history can be obtained from linking Alcohol and Other Drug Treatment Services NMDS (AODTS NDMS) with intentional self-harm data (e.g., hospital admission or coronial) to identify individuals with multiple rehabilitation service contacts. Loneliness is not a variable found in any existing health or police datasets, which may be in part due to the difficulty in quantitatively measuring the self-perception of isolation. Several survey-based scales have been proposed in the literature³⁴ to measure loneliness but none are known to be used in any of the aforementioned state or national datasets. A measure of loneliness could be incorporated into GP clinics or mental health service visits as quick surveys.

There are five possible levels of rurality/remoteness that can be assigned to individual SA1s³⁵. As SA1s aggregate to make SA2s, which is the preferred level of granularity, there needs to be a way to aggregate the

³⁰ <https://meteor.aihw.gov.au/content/index.phtml/itemId/726951>

³¹ <https://www.abs.gov.au/ausstats/abs@.nsf/Lookup/2033.0.55.001main+features100132011>

³² <https://www.aihw.gov.au/getmedia/b70c6e73-40dd-41ce-9aa4-b72b2a3dd152/18303.pdf.aspx?inline=true>

³³ <https://www.sprc.org/sites/default/files/resource-program/2016%20Montana%20Suicide%20Mortality%20Review%20Report.pdf>

³⁴ <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2394670/>

³⁵ <https://www.abs.gov.au/websitedbs/d3310114.nsf/home/remoteness+structure>

rurality/remoteness levels to a SA2 level - recalculation of the Accessibility Remoteness Index of Australia (ARIA) for individual SA2s may be necessary³⁶.

5.3.5. Analytics

In general, analysis maturity is relatively low across the PHNs included in the project, there are exceptions with a small number of PHNs who have moved into more advanced analytics. It will be important as more data becomes available to move from reporting and “intelligence” level analyses, to more advanced analytics where capabilities allow. Some PHNs have suggested inclusion of hypothesis testing (e.g., t-tests) in the future Portal, which can allow determination of statistical significance in changes of suicide numbers or rates. This can be useful for identifying emerging trends or evaluating the efficacy of suicide prevention activities. Time series analysis techniques such as X11 decomposition can be used to distinguish true from periodic time trends³⁷. A strong desire for greater geospatial analysis (e.g., statistical and/or greater disaggregation) and presentation was expressed by PHNs. Particularly, being able to look at the prevalence of certain risk factors and priority populations in different locations on a geospatial map was desired. It is recommended to incorporate a geospatial information system (e.g., ArcGIS) into the Portal to increase geospatial visualisation capacity.

As these analyses and presentations become more complex, a resource to help interpret the data analytics for PHN users with less data literacy will become more necessary. We recommend building on top of the glossary on the AIHW public monitoring site and making some definitions as pop-up elements in the data tables or interactive geospatial maps.

As the complexity and volume of data increases then the type and complexity of analyses should increase too.

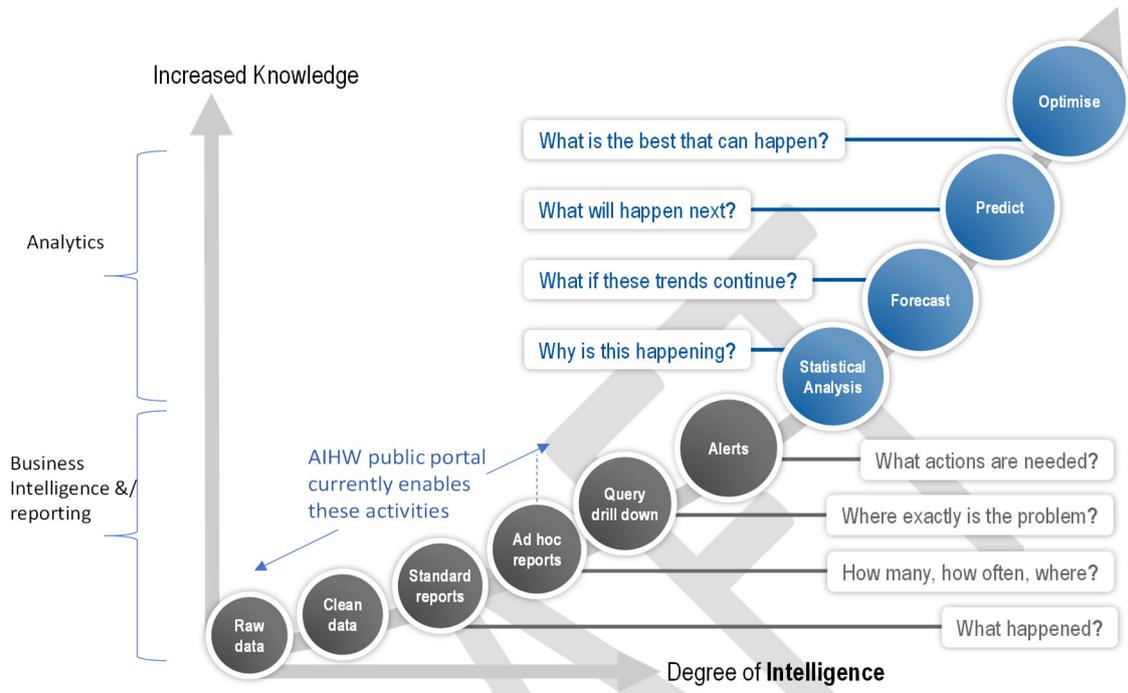
Figure 9 summarises the different stages of increasing the level of sophistication in intelligence through business intelligence through to more advanced analytics

³⁶ <https://www1.health.gov.au/internet/publications/publishing.nsf/Content/ARIA-Review-Report-2011~ARIA-Review-Report-2011-2~ARIA-Review-Report-2011-2-2-3>

³⁷

<https://www.abs.gov.au/websitedbs/d3310114.nsf/4a256353001af3ed4b2562bb00121564/c890aa8e65957397ca256ce10018c9d8!OpenDocument>

Figure 9: Typical progression of analytics maturity.



Examples of specific analyses that are linked to the different levels of maturity and degrees of intelligence provided are found in Table 7.

Table 7: Example of outputs as analysis capability matures.

Descriptive Analysis – What has happened? When and where did it happen?	Diagnostic – why is it happening?	Predictive Analysis – what will happen next?	Predictive Analysis – what will happen next?
Standard reporting and counts	Determining the drivers and impact of specific behaviours	Trends and forecasting	Apply and measure 'next best intervention'
Custom reports	Diagnostic journey or pathway analyses	Risk scoring or ranking at LGA level	'Real-time' services optimisation

Descriptive Analysis – What has happened? When and where did it happen?	Diagnostic – why is it happening?	Predictive Analysis – what will happen next?	Predictive Analysis – what will happen next?
Regional & rurality sub- analysis	Initial Impact analysis	Emerging threats, problem areas, segmentation analyses	Data streaming and alerts
Location and geo-spatial	Diagnostic analysis of network relationships (for example, associates and close contact behaviours)	More detailed impact analysis – additional factors, more complex approach	Optimisation of resources – matching resources to needs optimally

DRAFT

5.3.6. Data Linkage

The 2020 Mental Health Inquiry by the Australian Government Productivity Commission explicitly recommended the need for linkage of data sets collected at different government levels to maximise their utility³⁸. Data linkage, also referred to as record linkage, is the process of identifying, matching, and merging records that correspond to the same persons across multiple datasets using common identifiers.

Data linkage offers numerous benefits to its users as it can help identify factors and associations that would otherwise be difficult or impossible to determine, such as the uptake of treatments or assessing adverse outcomes under real world conditions.

The requirement of each dataset is that it must contain sufficient identifying information of the individual(s) of interest (e.g., set of demographic variables or unique identification number such as Medicare number). The general steps involved in (research) data linkage are³⁹:

1. All identifying variables (e.g., demographic variables, unique identification numbers) from each dataset to be linked are to be provided to the linkage personnel.
2. The linkage personnel will link the identifying variables from the multiple datasets, usually using a 'deterministic' or 'probabilistic' linkage approach.
 - Deterministic linkage – linkage based on one-to-one match of some unique identification number common to each dataset (e.g., a Medicare number appearing in two health datasets to be linked).
 - Probabilistic linkage – linkage based on the number of matching variables between the datasets (e.g., if address, age, sex, and name variables match between the datasets, then it is probable they belong to the same individual). Weights can also be applied to the variables for better accuracy.
3. Once linkage is complete, a project-specific identification number is generated for the linked record. The identifying variables will then be deleted by the linkage personnel.
4. The project-specific identification number will then be provided to the researcher(s) along with the non-identifying variables of the linked datasets. The researchers must not have access to the identifying variables of the original datasets.
5. The researcher(s) are then responsible for merging records that correspond to the same persons across multiple datasets to answer the research question (e.g., health care utilization by a specific population of interest).

³⁸ <https://www.pc.gov.au/inquiries/completed/mental-health/report/mental-health-actions-findings.pdf>

³⁹ <https://www.phrn.org.au/media/80613/aedc-data-linkage-policy.pdf>

-
6. The linked dataset is usually required to be deleted by the researcher at the conclusion of the research project unless a retention plan has been agreed upon.

Whilst data linkage infrastructures across Australia have developed to incorporate the routine linkage of core administrative datasets, there is potential to expand current efforts to include the linkage of national, state, and local data systems. Such an expansion would allow suicide prevention efforts to better assess the broader impact of suicide, care pathways before and after a suicide crisis, and factors associated with suicidality.

For example, inclusion of emergency service data (e.g., police, ambulance, and mental health crisis assessment teams) could be used to inform contact with frontline services that may be missing from current administrative hospital data. Further potentials of data linkage projects are detailed below:

- Identify event-level, individual-level, and area-level factors that are associated with suicide.
- Identify individual-level suicide method substitution to inform means restriction activity.
- Identify early warning signs of suicidality (e.g., contacting services), so that interventions can be implemented.
- Identify suicide clusters, as well as factors which increase the likelihood completed suicides and suicide attempts being part of a cluster.
- Insight into health service utilisation to identify trends in order to prioritise service implementation, including care received following a recorded suicide crisis.
- Insight into evaluation activities of suicide prevention initiatives (e.g., doing cost-benefit analysis).
- Increased accuracy in data sources and identify information that would be missed in non-linked data sources (e.g., admitted as suicide attempt but not recorded as such in [Emergency Department](#) presentations).
- Generate larger datasets with more variables (e.g., previous mental health diagnosis, contact with mental health services), allowing establishment of greater statistical significance in trends.

6. What Happens Next?

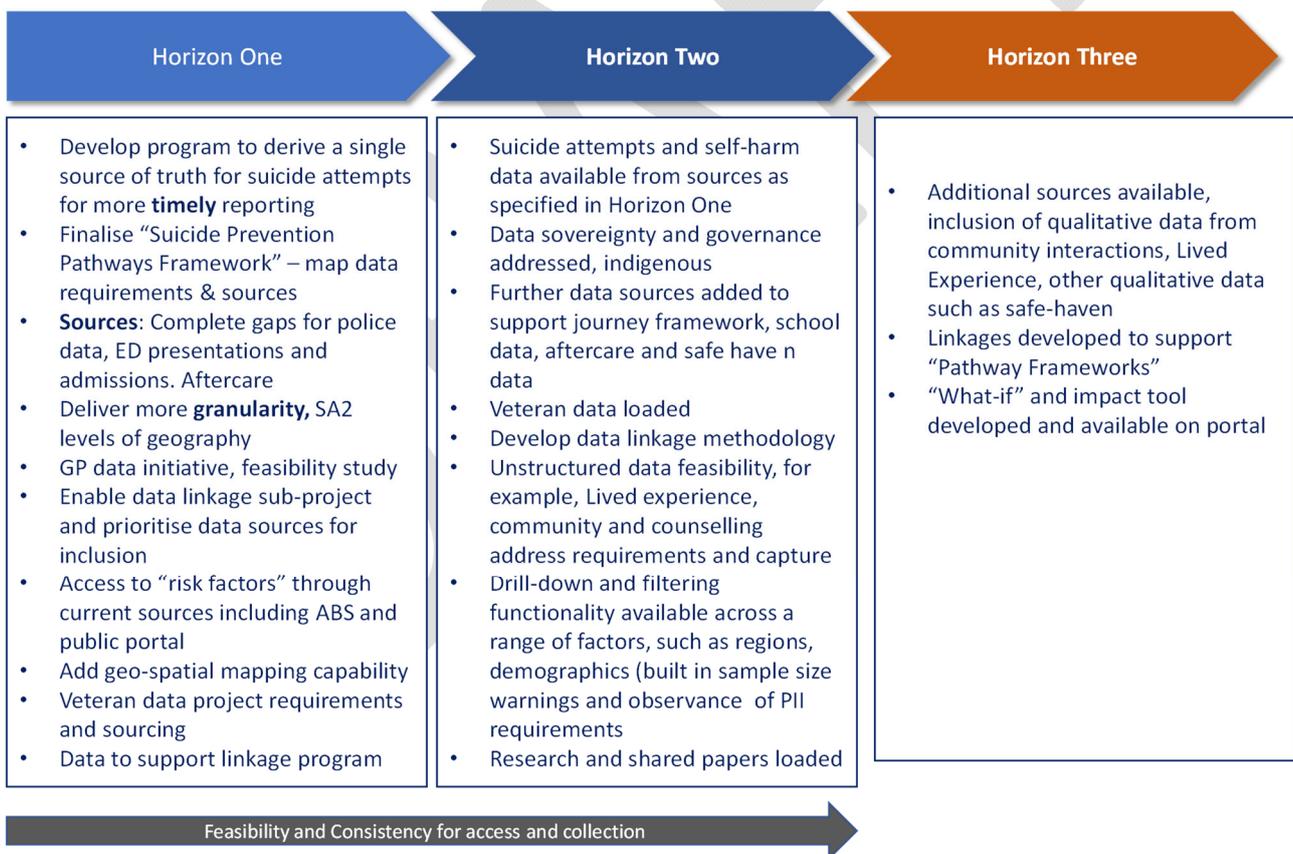
6.1. Key Milestones and Roadmap

Several of the recommendations previously discussed require a level of prioritisation for implementation. This report highlights several key suggestions from the PHNs.

Figure 10 gives a high-level view of key tasks and deliverables required to deliver the Portal. There will be several up-front feasibility studies required and smaller sub-projects to assess and scope some of the initiatives. Horizon time frames are initial estimates.

For example, the data linkage initiative will require a detailed scoping exercise to understand dependencies and approaches.

Figure 10: Activities and initiatives for data related activities over time horizons.



Appendix A. Workshop Details

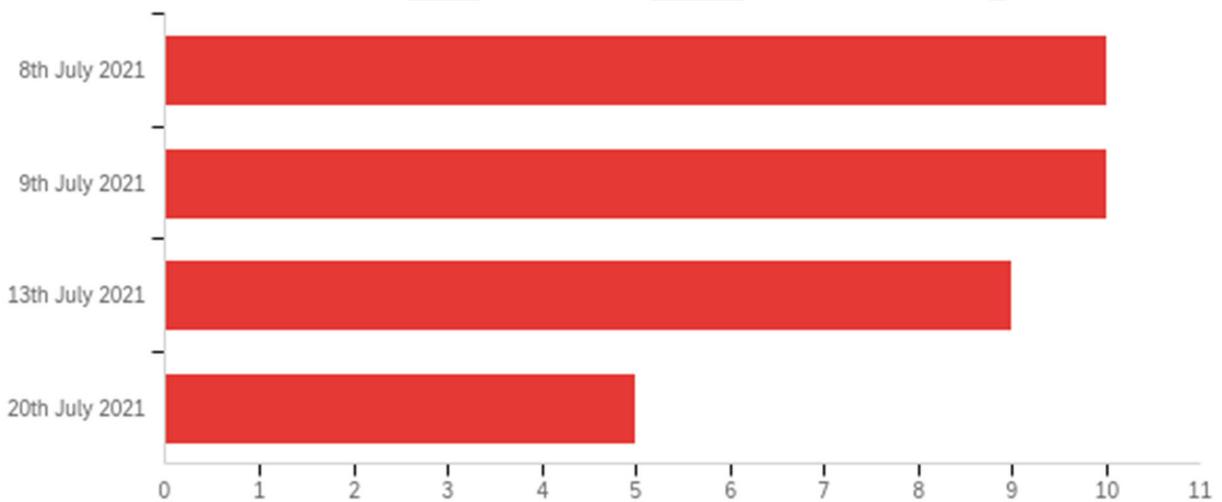
A.1. Pre-Workshop Survey Responses

Q1 - Which Primary Health Network do you work for? If 'other' organisation, please specify.

CQ WB SC PHN
black dog institute
DoH
Northern Territory PHN
Western PHN
Primary Health Tasmania
Primary Health Tasmania
WA Primary Health Alliance
Northern Territory
Brisbane North
Various
Black Dog Institute
Healthy North Coast
COORDINARE - PHN for SE NSW
lived experience rep
Country SA PHN
Nil. Participating as a lived experience advocate
Lived experience participant
Western NSW
NWMPHN
Department of Health
North Western Melbourne
NMHC Lived Experience group
South Eastern NSW PHN

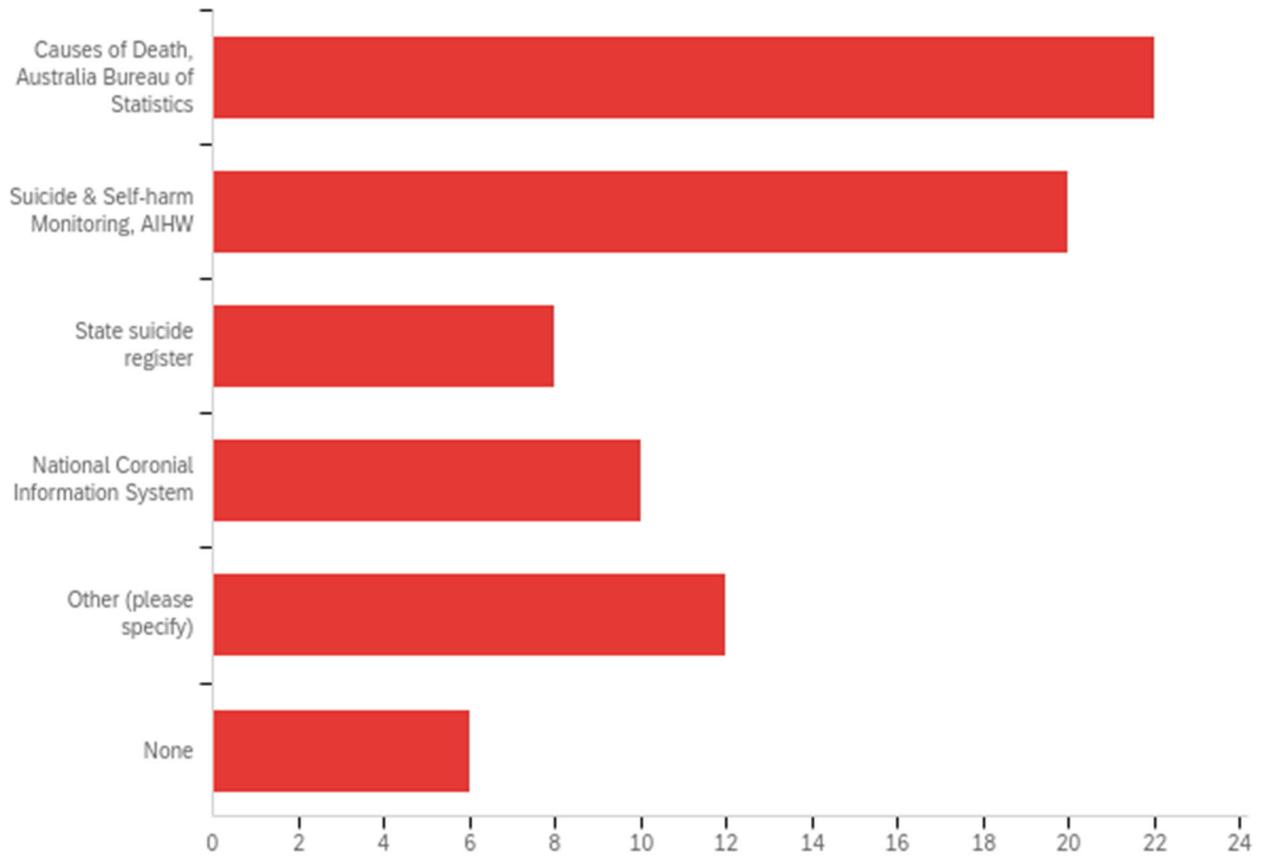
South Eastern NSW
Brisbane North
Mental health volunteer
Lived Experience
Orygen
Kimberley Aboriginal Medical Service
Department of Health (PHN Policy and Performance section)
North Western Melbourne
WAPHA
Central Queensland, Wide Bay, Sunshine Coast PHN

Q2 - Which workshop are you attending?



#	Answer	%	Count
1	8th July 2021	29.41%	10
2	9th July 2021	29.41%	10
3	13th July 2021	26.47%	9
4	20th July 2021	14.71%	5
	Total	100%	34

Q3 - What data sources on suicide and/or self-harm have you used to inform your suicide prevention activities?



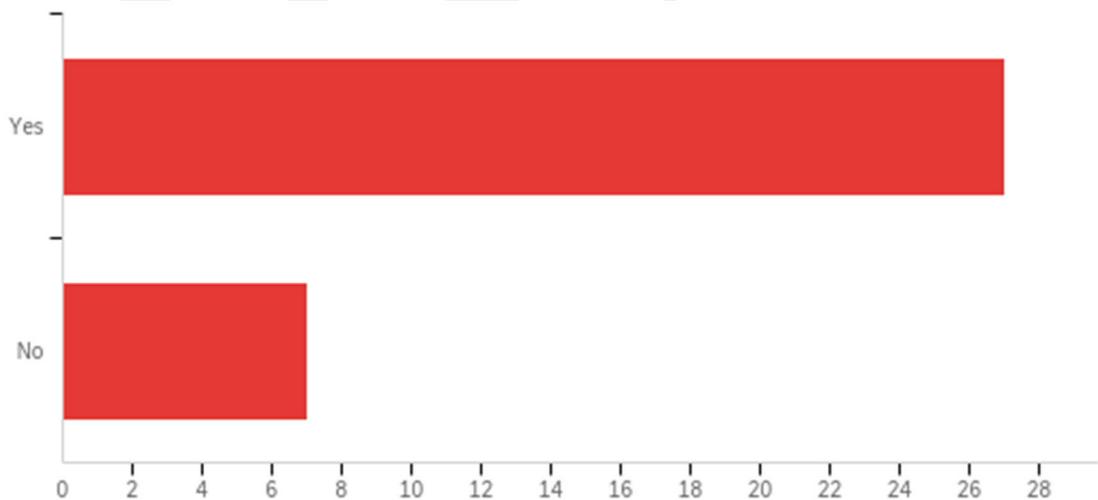
#	Answer	%	Count
1	Causes of Death, Australia Bureau of Statistics	28.21%	22
2	Suicide & Self-harm Monitoring, AIHW	25.64%	20
3	State suicide register	10.26%	8
4	National Coronial Information System	12.82%	10
5	Other (please specify)	15.38%	12
6	None	7.69%	6
	Total	100%	78

Q2_5_TEXT - Other (please specify)

VPU
AIHW Mort Books, PHIDU
Tasmanian Public Hospital Admitted Patient Care and Emergency Department datasets
Commissioned activity from AISRAP regarding local trends
NSW Health APDC and Ambulance
BDI LifeSpan Suicide Audits
Local Health and Police data
Lived Experience
Queensland Suicide Registry (AISRAP)
Lived Experience
ATSIPEP framework, Commitment to Aboriginal Youth Wellbeing
Queensland Police Data local to PHN region

Q4 - Are you aware of the existing AIHW Suicide & Self-harm Monitoring section within the AIHW website?

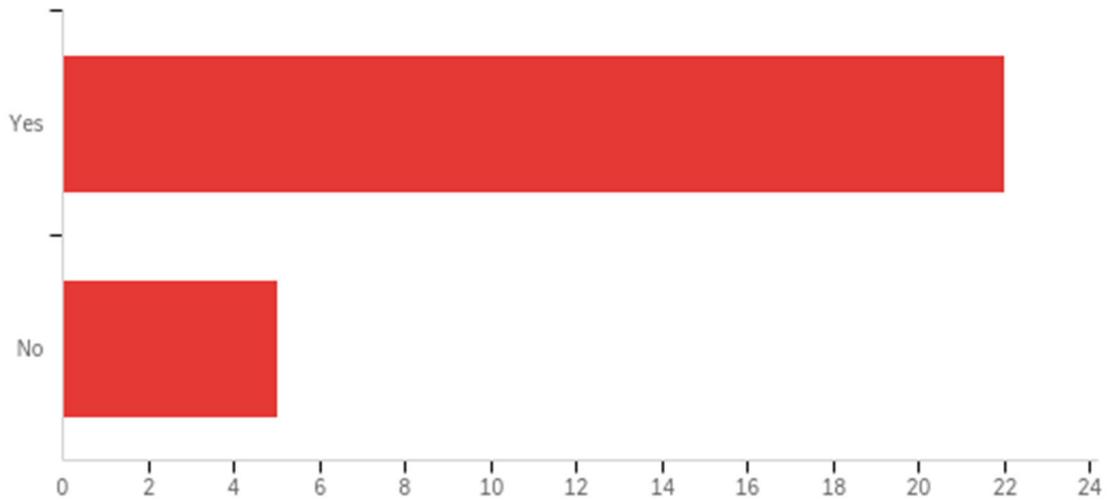
(<https://www.aihw.gov.au/suicide-self-harm-monitoring>)



#	Answer	%	Count
1	Yes	79.41%	27
2	No	20.59%	7

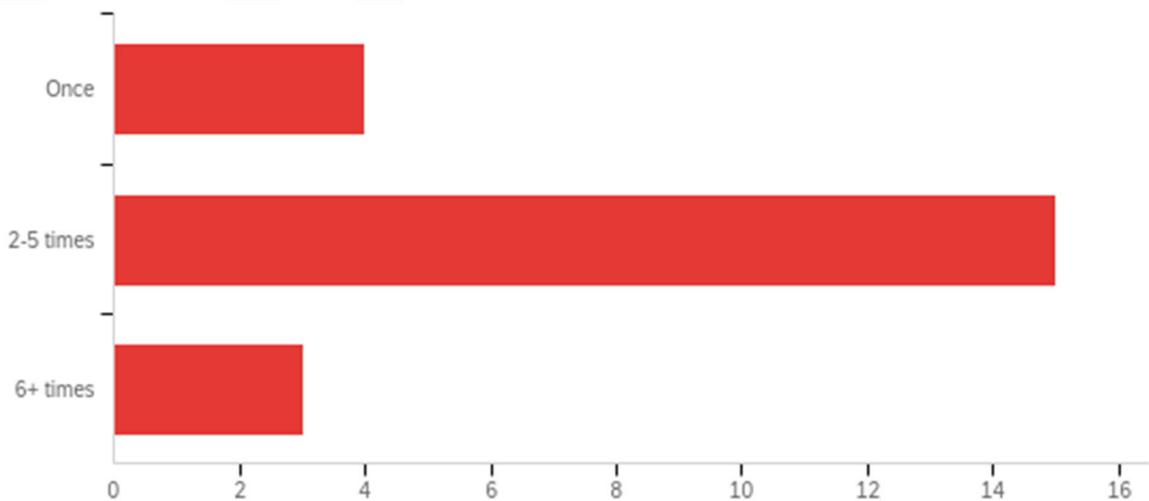
	Total	100%	34
--	-------	------	----

Q4a - Have you accessed the Data section of the AIHW Suicide & Self-harm Monitoring site before?
 (<https://www.aihw.gov.au/suicide-self-harm-monitoring/data>)



#	Answer	%	Count
1	Yes	81.48%	22
2	No	18.52%	5
	Total	100%	27

Q4b - Please specify how frequently you have accessed the Data section within the AIHW site.

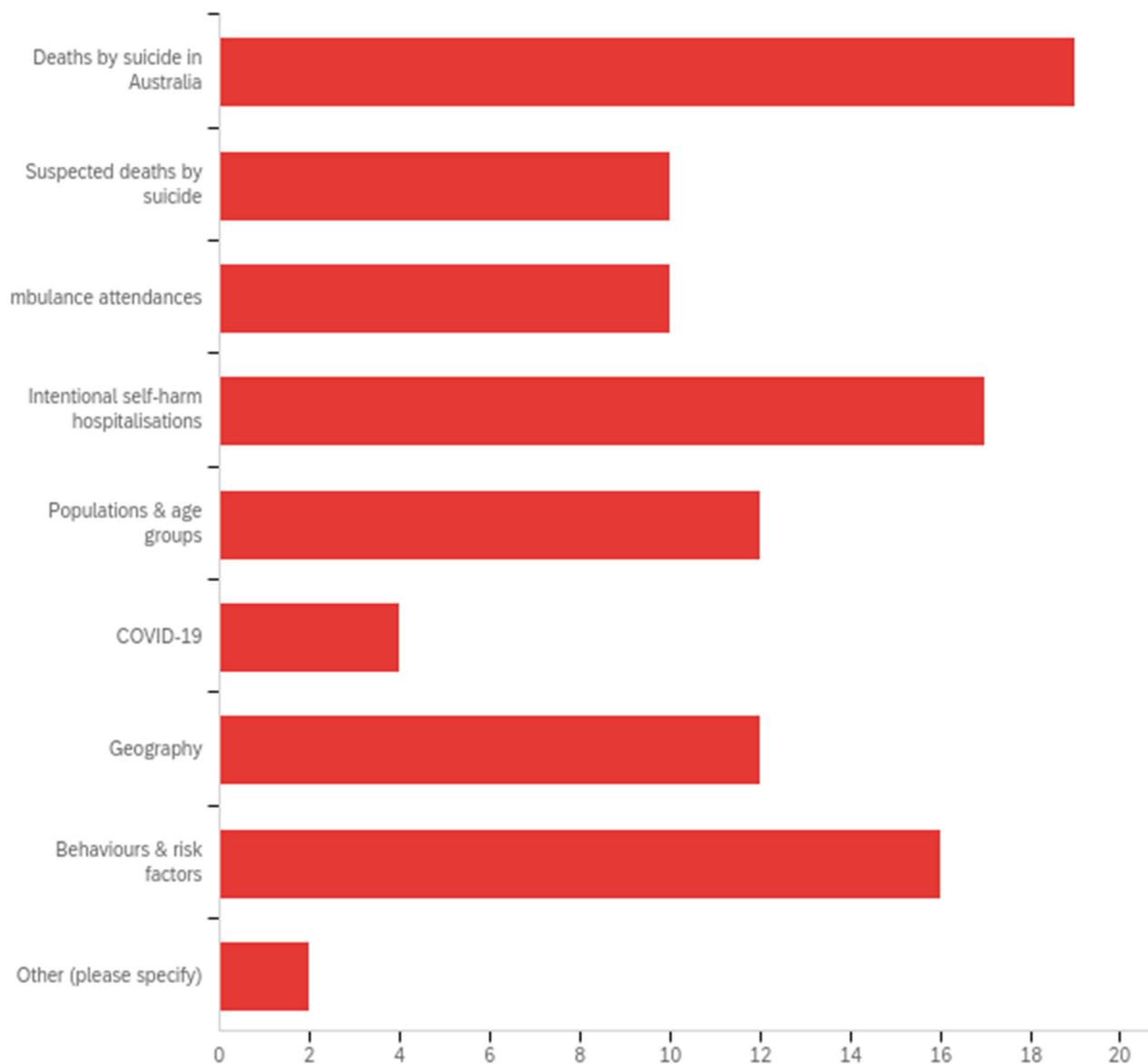


#	Answer	%	Count
2	Once	18.18%	4
3	2-5 times	68.18%	15
10	6+ times	13.64%	3
	Total	100%	22

Q5 - Are there any specific reasons why the AIHW site does not inform your suicide prevention activities? If so, please specify.

n/a
I'm very new to this
Funding is often set by DoH
Have not had need for it in the work that I am involved with in suicide prevention
Have not be directly recommended it

Q6 - Please specify any of the following Data section pages that you found useful (select all that were useful).



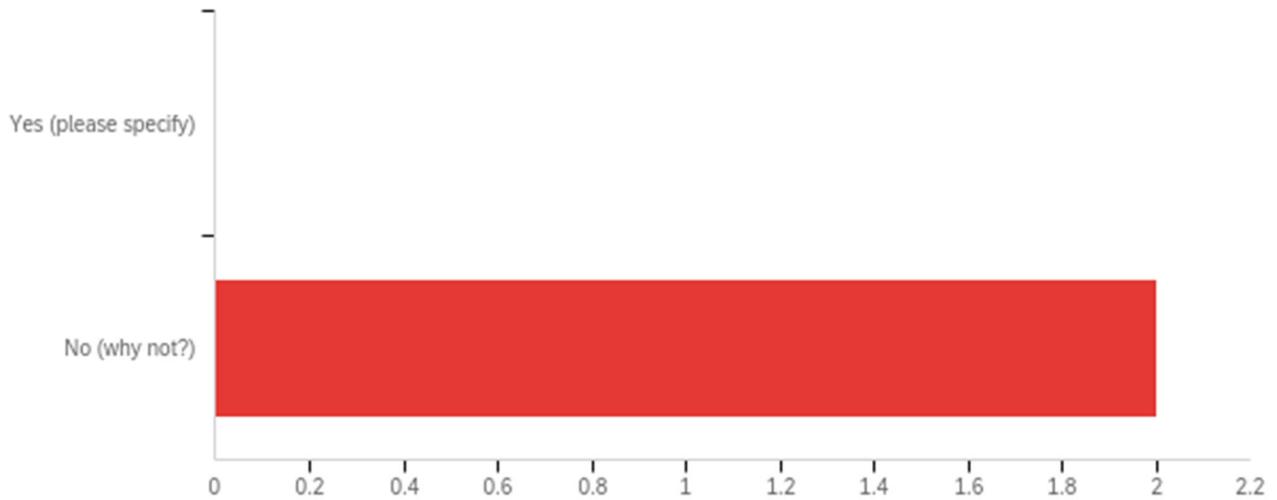
#	Answer	%	Count
4	Deaths by suicide in Australia	18.63%	19
5	Suspected deaths by suicide	9.80%	10
6	Ambulance attendances	9.80%	10
7	Intentional self-harm hospitalisations	16.67%	17
8	Populations & age groups	11.76%	12

9	COVID-19	3.92%	4
10	Geography	11.76%	12
11	Behaviours & risk factors	15.69%	16
14	Other (please specify)	1.96%	2
	Total	100%	102

Q5_14_TEXT - Other (please specify)

As part of the EAG
Cultural

Q7 - Do you use any data to inform your suicide prevention activities?



#	Answer	%	Count
1	Yes (please specify)	0.00%	0
2	No (why not?)	100.00%	2
	Total	100%	2

Q6_1_TEXT - Yes (please specify)

Q6_2_TEXT - No (why not?)

Not currently in scope for my role
This is my first doing any suicide prevention work.

A.2. Prioritising Data Needs (Ranking Poll Survey Results)

Question 1	Ranking Score*
What is most important to you in data? (Please rank)	
Timeliness (close to real-time as possible)	4.89
Granularity (e.g., greater geospatial detail in data)	3.78
Accessibility (ability to attain data with minimal steps)	3.67
Sensitivity (ability to detect 'true' suicide rates)	3.11
Completeness (minimal missing data)	2.89
Cleanliness (ability to use data as is)	2.67
Question 2	Ranking Score*
What is the greatest challenge you've had with data? (Please rank)	
Timeliness (not close enough to real-time)	4.73
Granularity (lack of smaller details)	4.18
Accessibility (difficult to attain datasets)	3.91
Sensitivity (unable to detect 'true' suicide numbers)	3.18
Completeness (lots of missing data)	2.64
Cleanliness (requires additional cleaning before analysis)	2.36

*Calculated by averaging the total score points by number of responses, for each poll option.



Appendix B.

B.1. Data Sources

PHN	ABS	AIHW	Coronial & Registry NCIS	Hospital & ED	Interviews ¹	State or Local Health	Research & Evaluation	Black Dog	Police	Other ³
North Coast	✓		✓			✓		✓ ²		
NW Melbourne		✓	✓		✓		✓			✓
Western NSW					✓	✓			✓	
Brisbane North		✓	✓		✓					
Country SA	✓	✓	✓	✓	✓					
SE NSW	✓	✓	✓	✓			✓	✓	✓	✓
NT		✓								
Tasmania		✓		✓		✓				
WA	✓	✓	✓							
Central QLD	✓	✓		✓					✓	
Kimberley Aboriginal MS			✓							✓

¹ Includes, sourced from *Lived Experience*, “on-the-ground” and community consultations

² Suicide Data Analytics Report is a suicide audit report BDI provided to North Coast PHN

³ PMHC, MHS, other ‘social’ such as bereavement support, employment data Medicare Benefits, Medical Message Exchange (MMex)

B.2. Lived Experience Advisor Feedback and Comments

The following comments (summarised) were received from the Lived Experience advisors after presenting the PHN workshop findings:

- The workshops have been focused on PHNs as users of potential data to be accessed through the PORTAL), however, PHNs should also supply and share data, including with GPs.
- There is some uncertainty around where suicide attempts statistics come from. The Lived Experience participants believed that attempt data is at best an estimate without much grounding, stating these statistics vary significantly between presentations (e.g., some advocates are saying 65,000 attempts per year, whereas others are saying 100,000 attempts per year). Having solid evidence for where these numbers come from is important.
- Definition is inconsistent, for example, self-harm numbers are commonly defined as hospitalised self-harm cases, which can lead to significantly underrepresentation of true self-harm numbers. Lived Experience contributors believe a consistent dictionary of self-harm terminology will be key to clarifying statistics that can easily be misrepresented.
- Several data sources, for example GP, police, hospital, ambulance, and schools are already available as the data are stored electronically, but not easily accessible. The federal government is supporting GPs through the Medicare scheme; however, data is not easily assimilated. The ability to better share data between these sources requires dedicated focus.
- Police are often the first point of contact for suicide attempts and record the data. But this data is just kept by the police and not shared where it needs to be.
- Data is not being shared between services. When people start a new service, they have to recount their lived experience, which can result in them being reminded of the trauma of an attempt. Understanding that privacy concerns limit the amount of data sharing, but this should also be something they lived experience person should have a say in. If they want their data shared to another service, they should have the choice to be able to give that permission.
- Government should be able to notify people what services are available to them and what they cannot access, for example, due to different locations. Another suggestion is that they should try to use technology (e.g., Google, Facebook) to recommend services to people based on their browsing behaviour.
- Suicide survivors are a priority population that is often overlooked in data collection (e.g., survey by Suicide Prevention Australia). They need to be considered in prevention strategies and data more strongly. Further, the advocacy for suicide survivors and people with suicidality history is not as strong as the advocacy for other priority populations such as LGBTQIA+.

B.3. Workshop Attendees

Name	Organisation	Role	Workshop and follow-up (F) session attended
Aimee McNeill	North Coast PHN	MHAOD Senior Manager	1, F
Gail Musolini	North Coast PHN	Senior Data and Reporting Analyst	1, F
Liam Wright	North Coast PHN	Senior Manager Big Data	1
Susan Cadman	North West Melbourne PHN	Manager Priority Populations	1, F
Jo Read	North West Melbourne PHN	Suicide Prevention Coordinator	1
Jackie Cerati	North West Melbourne PHN	Needs Assessment	1
Jan Hester	North West Melbourne PHN	Needs Assessment	1
Owais Rahid	North West Melbourne PHN	Needs Assessment	1
Mark Davis	National Mental Health Commission	Lived Experience Representative	1
Hayley Purdon	National Mental Health Commission	Lived Experience Representative	1
Kirsty Smith	Western NSW	Suicide Prevention - Senior Project Officer	1, F
Sherry Morris	National Mental Health Commission	Lived Experience Representative	1
Sue Hackney	Western NSW	Suicide Prevention - Manager	1
Kate Lehmensich	Department of Health	Observer	1, F
Clara Barrs	Department of Health	Observer	1
Jacob Grooby	Department of Health	Observer	1
Jennifer Allison	AIHW	Observer	1, F
Anna Fiego	University of Melbourne	Observer	1,2,3,4,F
Tanya Ranieri	Brisbane North	Suicide Prevention Coordinator	2
Carla Taylor	Brisbane North	Evaluation & Procurement Officer	2
Graeme Holdsworth	National Mental Health Commission	Lived Experience Representative	2
Jo Riley	South East NSW	Program Manager Suicide Prevention	2
Abhijeet Ghosh	South East NSW	Population Health Planning & Information - Manager	2, F
Nerida Lawrentin	South East NSW	Suicide prevention - Project coordinator	2
Anwyn Ladwinski	National Mental Health Commission	Lived Experience Representative	2
Chez Curnow	Country South Australia	MHOAD Manager	2
Hayley Colyer	Country South Australia	Suicide Prevention Coordinator	2, F

Name	Organisation	Role	Workshop and follow-up (F) session attended
Jenny Smith	National Mental Health Commission	Lived Experience Representative	2
Georgia Dempster	University of Melbourne	Observer	1,2,3,4, F
Nerida Volker	Lived Experience	Observer	2, F
Natalie Paris	Northern Territory PHN	Suicide Prevention Coordinator	3
Jessica Flavel	Northern Territory PHN	Health Intelligence Analyst	3, F
Bella Burns	Northern Territory PHN	MHAOD Manager Strategy	3, F
Safia Desai	Northern Territory PHN	Senior Project Officer	3
Saman Farahangiz	Primary Health Tasmania	Needs Assessment	3
Liz Everard	Primary Health Tasmania	Suicide Prevention	3
Michelle Kudell	Primary Health Tasmania	Suicide Prevention	3
Tracy Richardson	Primary Health Tasmania	Suicide Prevention	F
Sarah Collingridge	Western Australia PHA	Needs Assessment	3, F
Christina Read	Western Australia PHA	Needs Assessment	3
Jon Pfaff	Western Australia PHA	Senior Policy Advisor	3, F
Chris Wood	Department of Health	Observer	3
Erika Mackay	Central Queensland, Wide Bay, Sunshine Coast PHN	Suicide Prevention	4, F
Marlee Lucht	Central Queensland, Wide Bay, Sunshine Coast PHN	Suicide Prevention Coordinator	4, F
Trevor Pyman	National Mental Health Commission	Lived Experience Observer	4
James Burchmore	Mental Health Commission	Assistant Director, Monitoring & Reform	2,4, F
Kiamee Baguley	KAMS	Suicide Prevention Coordinator	4
Karl Williamson	KAMS	Senior Manager SEWB	4
Emily Unity	Lived Experience	Observer	4
Ray Martin	The Oasis, Townsville	Suicide Prevention Project Manager	4, F