NSW Health

Introductory guide to collecting self-reported information through surveys

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Acknowledgments

This document was collaboratively developed with NSW Health staff and in consultation with the Self-Reported Information Coordination and Engagement Working Group with direction from the Self-Reported Information Steering Committee and the Future Health Strategic Outcome 1 Steering Committee.

The document reflects:

- insights from a statewide stocktake of selfreported information collections coordinated by the Strategic Reform and Planning Branch and facilitated by local health district Directors of Clinical Governance
- the recommendations of the Strengthening and Streamlining Patient Experience report, written by a time-limited working group co-chaired by the Chief Executive, Bureau of Health Information and the Director, Information and Performance Support, Regional Health Division
- the system-wide guidance and expertise gathered through consultation with local health districts, in particular Directors of Clinical Governance and Patient Experience leads.
- key elements from the Hunter New England Local Health District Patient Reported Measures

 Governance and Management policy (HNELHD Pol 22_07: PCP 2).

Thank you to all stakeholders who provided their expertise and feedback in the development of this document.

Where can I get more information?

- For information about local procedures, contact your Clinical Governance Unit.
- For questions about the essential data governance requirements for self-reported information collections, email the Data Governance team, Ministry of Health via: moh-datagovernance@health.nsw.gov.au.
- To learn more about the strategic approach to self-reported information, email the Strategy and System Priorities Unit, Strategic Reform and Planning Branch, Ministry of Health via: moh-patientmeasures@health.nsw.gov.au.

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Purpose

This guidance provides direction to NSW Health staff collecting, using and disclosing self-reported information through surveys.

Self-reported information is outcome and experience feedback, collected by health service providers and system managers and responded to by patients, carers, community or staff. This feedback can be translated into structured information that tells us about the experiences and outcomes of care that matter most to patients.

Why is this important?

A consistent and coordinated system-wide approach to the collection and use of surveys is a Future Health priority. This approach will provide key insights into health outcomes and experiences and provide data for use by individuals, services, and the system by capturing the voices of patients, carers, community and staff.

The benefits of applying this guidance include:

- strengthening the actionability of data by better tailoring the data collected to its primary intended purpose, while more consciously planning to enable secondary purposes
- streamlining the volumes of data that are being collected but not optimally used, and avoiding the unnecessary collection of personal or health information
- supporting the use of complementary information across statewide and local patient experience data collections

- strengthening confidence that feedback is being heard and acted on, and the collection of data is optimised and embedded in practice
- reducing burden on patients and staff by managing the risk of unintentionally asking individual patients or staff to complete multiple surveys which may duplicate each other.

"Measurement is critical to understanding and tracking progress and improvements in human experience. For patient experience to be effective, we must design the right measures, for the right moments and the right purpose, while working to ensure consistency and comparability of results. We must evolve measurement systems to meet the needs of patients and enable staff to interpret and act on the findings."

Elevating the Human Experience - Our Guide to Action (NSW Health, 2020)

What is included in this guidance?

This guide supports NSW Health staff to plan, implement and manage surveys by:

- describing self-reported information surveys and their typical uses
- providing advice on when and how to use self-reported information survey collections including collection principles, best practice requirements and recommended data governance, security, and privacy considerations
- including considerations for local planning of new collections and the review of existing collections as well as a governance requirement checklist.

What else do I need to know?

- This guidance focuses on the purpose, management and governance of collecting self-reported information through surveys. It doesn't specify the tools or information technology (IT) platforms that should be used to collect information.
- The guidance supports the design and implementation of surveys for the purpose of quality improvement and performance monitoring only. Surveys for peer reviewed and publishable research studies are not included.
- The guidance complements guidelines, policies, procedures and associated platforms supporting the collection of other types of feedback that should also be read. Links to these are provided throughout the document.

Glossary

Acronym or term	Definition
Feedback landscape	The range of ways self-reported information is received from patients, carers, the community and staff.
Health information	Personal information or an opinion about a person's physical or mental health or disability, or a person's express wishes about the future provision of health services for themselves, or a health service provided, or to be provided, to a person. NSW Health Privacy Manual for Health Information
Patient Reported Experience Measure (PREM)	Survey questions that capture patient experiences of healthcare or services.
Patient Reported Outcome Measure (PROM)	Survey questions that capture patient perspectives of how illness or care impacts on health and wellbeing such as quality of life, daily functioning and symptoms.
Personal information	Any information or an opinion about a person whose identity is apparent or can reasonably be ascertained from the information or opinion. NSW Health Privacy Manual for Health Information
Self-reported information (SRI)	Outcome and experience feedback, collected by health service providers and system managers and responded to by patients, carers, community or staff. This feedback can be translated into structured information that tells us about the experiences and outcomes of care that matter most to patients.
SRI survey	A method of seeking structured feedback about patient experience or outcomes, from their perspective and based on well-established evidence.
SRI survey collections	A data set collected by NSW Health, statewide and through local health districts/specialty health networks, as well as other state and national health/government organisations.
Survey streams	Four survey designs that can be used for capturing self-reported information; rapid view, reflective, point of care and population view.

Self-reported information surveys and their uses

Self-reported information surveys collect information based on wellestablished evidence of what matters most to patients and what drives positive outcomes of care.

Self-reported information is collected from patients, carers, the community and staff. It tells us what matters and is essential for delivering high-quality care.

Collecting self-reported information enables measurement and analysis for multiple uses at the individual, service and system levels to inform and improve service delivery and planning and to drive continuous quality improvement.

NSW Health collects information about patient outcomes and experiences in many ways, detailed in Figure 1. By collecting feedback through a survey, NSW Health can collect structured information about experiences of care, health status and wellbeing that enables measurement and analysis for multiple uses at the individual, service and system levels.

Unlike other types of self-reported information, surveys directly seek the perspectives of the people being surveyed and are structured in nature.

Figure 1. A snapshot of NSW Health feedback pathways



Surveys

media



governance committees and partnerships



management and complaints



Feedback assist widget



Patient stories



consumer walkarounds



programs (for example REACH)

^{*}The diagram is illustrative and not exhaustive

There are four self-reported information survey streams including rapid view, reflective, point of care and population view

Self-reported information **surveys** are where health services **directly seek information** from the patient, carer, or community's perspective through structured questions. These questions are validated where possible and are based on well-established evidence of what matters most to people and what drives positive experiences and outcomes of care.

The survey streams, in Figure 2, are different styles of surveys that can be used to understand the outcomes and experiences of patients, carers, community and staff. The four survey streams are better suited to different primary and secondary uses that help to determine what and when to collect information as well as who to collect information from.

Information from different survey streams can provide actionable insights into the health outcomes and experiences of patients, carers, the community and staff. For example, when the same question is used in both a rapid view and reflective collection the two data sets can be used together to better understand the experience of patients receiving care.

Rapid view, reflective and population view survey responses are treated **confidentially** and are not shared in an individually identifiable way with care providers. For record linkage and other purposes, the information may be **identifiable** by appropriately authorised administrators of the data collection in compliance with all relevant NSW and Commonwealth legislation, regulation and policies including NSW delegations.

Figure 2. Self-reported information survey streams

Streams	Description
Rapid view	Information collected via a survey within 72 hours of a clinical interaction for rapid-cycle safety and quality improvement.
COO COO Reflective	Representative information, collected via a survey following a clinical interaction when outcomes have materialised, for fair comparison and performance measurement along the care journey and across the health system.
Point of care	Information collected via a survey before or during a clinical interaction to inform real-time shared care planning and clinical decision making. This information is intentionally identifiable so healthcare providers can use it with patients to inform care. It can also be collected longitudinally to enable analysis of trends over time for the individual or patient cohort.
ুট্≣ ভু ⊑্∕ Population view	Representative or census-based information collected via a survey about health behaviours, status, risk factors and general experiences to inform the design and monitoring of preventative health programs, system planning and performance measurement.

The four surveys streams serve different primary and secondary uses

Surveys are issued for a range of different health-related activities. Figure 3 recommends survey streams based on the primary and secondary purpose of a collection. Local collections, designed and implemented by local health districts, are typically rapid view. Survey purpose should be understood before deciding on a survey type to ensure the method of collection will satisfy the reason for and needs of the survey.

Other feedback pathways such as compliments, patient stories, website feedback pages, letters, emails and social media can complement survey findings. There are also policy-driven feedback pathways including complaints, open disclosure, and Recognise, Engage, Act, Call, Help (REACH).

Information collected through the range of ongoing state and local feedback pathways can fulfil the Australian Commission on Safety and Quality in Health Care's accreditation requirements and should be utilised for this purpose.

Any new survey collection should align with the <u>Self-reported information collection principles</u>, detailed in the next section of this document.

Figure 3 can be used to guide decision-making about which survey stream is best suited to a local collection.

Figure 3. Survey streams and the recommended primary and secondary purposes

Use	Rapid View	Reflective	Point of care	Population view	Other types of feedback
Clinical decision-making			Primary		
Quality improvement	Primary	Secondary	Secondary		Secondary
Performance management		Primary			
Monitoring and evaluation	Secondary	Primary	Secondary	Secondary	
Policy development	Secondary	Secondary		Primary	
Public reporting		Primary		Secondary	
Complaints management					Primary

More information about self-reported information and the survey streams, including examples of statewide collections, are detailed in the supporting <u>fact sheets</u>.

Self-reported information collection principles

Strengthen and streamline measurement by applying the eight collection principles.

Patients, carers, the community and staff expect their feedback to be used in ways that inform NSW Health's efforts to improve safety, quality and experience. This requires compliant governance and best practice management of 'why', 'what' and 'how' patient experience data will be collected, analysed and used.

The principles, in Figure 4, support the collection of meaningful insights and actionable data that is used to impact change that matters to patients, carers, the community, staff and the system. With clear standards and governance arrangements in place, self-reported information provides essential safety and quality data for use at local and statewide levels.

Figure 4. Self-reported information collection principles

Person-centred

Surveys focus on what matters most to patients, carers, families, communities and staff, and what is most useful for improving care.

Proportionate

Data is collected once and used for multiple purposes to ensure the volume, frequency and duration of data collections minimise duplication and burden.

Governed

Resourced data management and governance plans are in place for collecting, reporting, sharing and responding to survey results to maximise their use and value.

Responsive

Survey results and insights are used at the service level to improve care and shared across the health system to support continuous improvement.

Accessible

Surveys and collection methods support participation by diverse populations and results are available to multiple audiences, including consumers.

Purposeful

Survey data collections produce meaningful insights and actionable data, and articulate how and by whom information will be used to improved outcomes, experiences, and safety.

Validated

Surveys are based on well-established eveidence and collection tools are fit for purpose.

Transparent

Surveys are accompanied by information on its purpose and how responses will be used.

Applying the SRI collection principles to local surveys and collections

Consider the following four best practice questions when reviewing or creating a new survey collection.

The best practice questions assist with applying the collection principles to **new and existing self-reported information collections** and are best answered in order.

- 1. Is a survey required?
- 2. Is the intent and purpose of the survey collection satisfying an identified need?
- 3. Does the survey collection meet essential policy requirements?
- 4. How will the information be reported and used at both the local and service level?

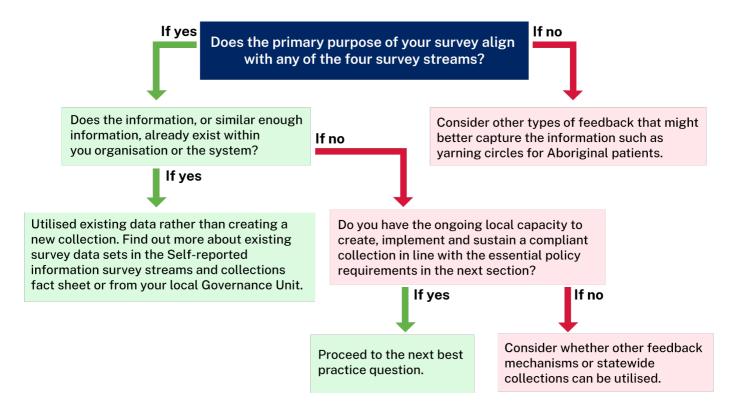
Question 1: Is a survey required?

A survey may not always be the most appropriate way to collect feedback about experience and outcomes

Information about patient outcome and experience exists in many forms that is readily accessible and has been captured in a way that is patient-centred. The creation, implementation and sustainment of a new collection must be justified and resourced appropriately for the lifecycle of the collection.

Figure 5 assists decision-making when creating a new, or reviewing the utility of an existing, collection.

Figure 5. Decision making for creating a new, or reviewing the utility of an existing collection



A checklist of key considerations and supporting information is included below for questions 2-4. It is expected that all checklist items are met before a new collection is commenced. If a requirement cannot be met, evidence-based reasons should be provided why not.

There is also a template at the end of the guide to collate evidence for local governance planning when creating a new or reviewing existing survey collections.

Question 2: Is the intent and purpose of the survey satisfying an identified need?

A new or existing survey collection should be needed and not already addressed by existing self-reported information survey data sets

A clear survey collection intent and purpose helps distinguish a survey collection from existing data sets by:

- filling an identified gap in the data.
- reducing survey burden and proliferation which ensures patients, carers and community are surveyed
 as little as possible. This is a key consideration when surveying priority populations including
 Aboriginal and/or Torres Strait Islander people, people from culturally and linguistically diverse
 (CALD) backgrounds, people with a disability, LGBTIQ+ people and refugees and asylum seekers.
- assisting staff to understand and use the range of collection data available across NSW Health.

When planning a new survey collection think about how the information will be used once it is collected, what kind of information you are collecting (outcomes, experiences or other information), who will be providing the feedback and the time and effort required to complete the survey relative to the benefit to the service. A time-limited collection may be suitable for quality improvement-focused or one-off collections.

Checklist item	If no, why?	For more information
Is the primary reason for collecting the data defined and supported?		Self-reported information surveys and their uses in this guidance
Is need for the information and its use aligned with one of the four survey streams and their typical uses?		Self-reported information surveys and their uses in this guidance
Have you mapped existing collections and how many surveys your survey recipient may receive from NSW Health?		Self-reported information surveys and their uses in this guidance
Does this collection or survey support NSW Health strategic priorities, local strategic plans or other state or national priorities?		For example, Future Health: Guiding the next decade of health care in NSW 2022-2032
Have you defined the patient cohort(s) your collection or survey targets?		Apply a sampling approach in this section
Can you apply a sampling approach to the collection of responses?		Apply a sampling approach in this section
Are you using an existing question set for your survey collection?		<u>Draw on established statewide</u> <u>question sets</u> in this section
Are you creating a new question set for your survey collection?		Draw on established statewide question sets in this section

More information about intent and purpose

Apply a sampling approach

Where possible, ensure surveys are sent to a sample of the survey population to avoid generating excessive amounts of data that do not provide greater insight or risk duplication and survey burden. Sampling is most typically applied to rapid view collections. In these cases, a census approach, which is surveying every patient, requires a compelling reason such as targeting a specific patient group or gaining insights about a small service with low patient numbers.

When designing a survey:

- if applying a sampling approach consider, what is the 'sufficient number of responses' required to support your purpose? What proportion of patients will be sampled? And how will the sample be recruited?
- if a sampling approach is not applied, consider how to monitor your collection for a sufficient number of responses.

Draw on established statewide question sets

Use established statewide question sets where possible to ensure the questions are evidence-based, enable comparability across collections and are suitable for targeted populations, where applicable. Existing question sets may be supplemented with additional questions or combined with other existing question sets to meet local needs.

When applying an existing question set, consider:

- how established the question set is
- whether it is validated
- the evidence supporting the effectiveness of the set.

If creating a new question set:

- determine why existing tools are unsuitable
- ensure the development of new questions are informed by consultation with targeted population groups/patient cohorts where applicable
- ensure any new questions build a coherent and reasonably comprehensive picture of a patient's experience, as defined by the key domains of NSW Health's Elevating the Human Experience.
- complete an <u>Aboriginal Health Impact Statement</u> to understand the considerations to be made for Aboriginal people participating in the survey
- identify duty of care requirements for monitoring and responding to information received through open survey questions with 'free text' response options.

The <u>Rapid Patient Experience Survey pilot</u> trials seven questions from the NSW Adult Admitted Patient Survey, aligned to the core domains of Elevating the Human Experience. A reflective question set in a rapid view collection enables timely quality and safety improvement at the service level and comparison across time and settings at a statewide level. These questions are well-established, evidence-based, have undergone cognitive testing with users and are considered meaningful and actionable.

The Bureau of Health Information has also published a series of minimum experience question sets including the <u>NSW Patient Survey Program</u> and <u>Aboriginal Patient Experience</u>.

Question 3: Does the survey collection meet essential policy requirements?

Compliance ensures data collections are managed and coordinated appropriately

Understanding the policy obligations and requirements for the collection, use and disclosure of self-reported information across the whole data lifecycle ensures effective, consistent and compliant data management and optimises the value of the data collected.

Self-reported information collections must comply with relevant NSW and national legislation, regulation and policies such as:

- NSW Health Privacy Manual for Health Information in conjunction with NSW Aboriginal Health Ethics Guidelines: Key Principles
- NSW Health Data Governance Framework
- Health Records and Information Privacy Act 2002 (NSW) (HRIP Act)
- Privacy and Personal Information Protection Act 1998 (NSW) (PPIP Act)
- NSW Health Privacy Management Plan
- NSW State Records Act 1998
- Electronic Information Security Policy Directive
- Complaints Management Policy Directive
- The Australian Code for the Responsible Conduct of Research
- National Statement on Ethical Conduct in Human Research

Key requirements

- The development of a collection notice A collection notice informs individuals that their personal and/or health information is being collected, why it is collected, what it will be used for, who the intended recipients are, whether they are required to supply information and the consequences if they don't, and any existence of a right to access or correction of the information they provide. The notice should also contain information on how to contact the agency that is collecting the information.
- A regularly audited register of endorsed self-reported information survey collections A register of endorsed self-reported information survey collections ensure greater visibility and understanding of active collections. This register must be monitored and audited regularly to ensure they continue to meet the requirements of this guide.
- An appropriately authorised group(s) to endorse self-reported information collections An
 appropriately authorised group has strategic and operational responsibility for local self-reported
 information collections such as the SRI Steering Committee or local Quality and Safety Committees.

Data Governance is the implementation of a set of policies, processes, structures, roles and responsibilities to ensure that an agency's data is managed effectively and that it can meet its current and future business requirements.

Data Governance Toolkit (Data.NSW, 2024)

Benefits

- Clarifies the roles and responsibilities for the establishment, design and development, management and decision making about access to and the use of self-reported information.
- Enhances decision making by providing clear guidelines on how to respond effectively to findings.
- Supports efficient and consistent allocation of resources in relation to the design, collection, storage and use, and analysis of self-reported information.

- Ensures that valuable feedback and complaints are properly managed and utilised for continuous improvement.
- Prevents over collecting data containing personal or health information beyond the scope of the survey.
- Ensures a wide range of stakeholders are engaged to determine the objectives and overall direction of data collection activities.
- Identifies requirements and provisions so that local processes support and are aligned with the broader governance and strategic direction of the self-reported information program.

Risks

- Misuse of sensitive personal and health information including inappropriate or unauthorised access to identified or potentially identifiable information.
- Self-reported information collections stated as 'anonymous' including identifiable or potentially identifiable personal information.
- Missed or untimely response to urgent safety or duty of care issues including when a request for further follow up contact is included by survey respondents in free text responses (<u>Complaints</u> Management Policy Directive).
- Mismanagement of manual data collections (hard copy responses) with no transcription into a compliant electronic system and inadequate shredding and disposal of documents after transcription.
- Failure to meet safety and security requirements for patient data.
- Duplication of effort or placing unnecessary burden on patients, carers, community and staff to provide feedback to multiple sources
- Inconsistent data collection practices, leading to an inability to leverage results to address safety and quality concerns.

Compliance with the essential governance requirements, in the <u>Governance planning template for local survey collections</u> at end of the guide, is encouraged to leverage associated benefits and mitigate governance-related risks.

Checklist item	If no, why?	For more information		
Does your collection comply with essential legal and data governance requirements?				
Have you established or utilised an existing local governance committee that is appropriately authorised to endorse and oversee the collection?		Governance planning template for local survey collections in		
Do you have support from local sponsors and governance committees to help ensure the collection is resourced, sustained and reviewed in line with legal requirements and data governance guidelines?				
Do people understand where and how their response will be used?		this guidance		
Can survey recipients find out where feedback goes, who sees it and how it is used?				
Can survey recipients find out what happened with their response and when they can expect something to happen?				

Question 4: How will the information be reported and used at both the local and service level?

Appropriate sharing of the self-reported information collected through surveys will guide decision-making at all levels of the health system

The insights arising from survey data is of interest to local health districts/speciality health networks, Ministry of Health, pillars, statewide health services, shared services and patients, carers, families and the community. A consistent approach to the collection process and the information collected through survey questions, including demographic information, ensures all parties can use and triangulate data collected to gain greater insights into the themes and patterns across various types of feedback.

For every data collection, local roles and responsibilities ensure:

- · managers, clinicians and staff can act on the results of the analysis
- clinical governance committees, local health committees, executive and the Board have local accountability and oversight.

Checklist item If no, why?

Have you confirmed whether the data will be used for performance monitoring?

Have you identified where and who the data will be reported to? And at what intervals?

Do you know what level of data analysis is needed?

Have you identified resources that will undertake analysis of the data to generate actionable insights? And resources to take action in response to findings?

Have you determined how often local teams will review the data for any patient or carer concerns that require immediate action?

Do you have statistical guidance on appropriate use and interpretation of results?

Do you have a plan in place to manage bias in your collection and reporting?

Can you provide survey respondents with access to a copy of their survey response upon request?

When sharing results publicly, is the information in an accessible format? And shared in a timely manner?

Do local processes ensure data is used for quality improvement and innovation as well as decision making and patient-centred care?

Do local processes support the involvement of consumers in co-designing change resulting from feedback?

More information for reporting and using survey information

Recognise patient survey results as essential safety and quality data and integrate the findings into clinical governance oversight at local and statewide level.

Escalation pathways ensure high-risk responses are managed appropriately

Arrangements need to be in place to support escalation of results, where appropriate, to ensure matters are managed in line with policy and best practice.

People understand where and how their response will be used

People who are invited to complete surveys should be able to find out:

- where feedback goes, who sees it and how it is used
- where to go to find out what happened with their response and when they can expect something to happen
- how to be involved in co-designing change resulting from feedback
- how we manage their personal or health information.

Where the survey data is identifiable, the health service issuing the survey should be able to provide an individual survey respondent with a copy of their survey response upon request. For example, this may be required if a survey respondent withdraws their consent following completion of the survey.

Visit the <u>Rapid Patient Experience Survey pilot FAQ</u> where consumer-informed frequently asked questions provide an example of the types of information to be shared.

Ensure readability for all consumer-facing materials

Test consumer-facing materials for their readability level. Materials should be as close to a Grade 7 reading level as possible to ensure all participants are able to understand and participate in the collection. In some cases, translation of the survey and materials is appropriate.

- The <u>NSW Health Accessibility Communications Policy</u> aims to support all NSW Health staff in developing communication materials that are accessible to consumers.
- The <u>Sydney Health Literacy Lab's Health Literacy Editor</u> can be used to test the readability of English language consumer-facing materials.

Engage consumers in collection implementation as well as quality improvement initiatives arising from the collection findings

Involve consumers in the implementation of new collections and the review of existing collections to ensure the collection can be accessed by as many eligible participants as possible and quality improvement solutions are consumer-informed/designed. Engagement with Aboriginal consumers may be necessary when implementing targeted surveys and quality improvement initiatives.

<u>All of Us: Engaging consumers, carers and communities across NSW</u> provides guidance on respectful engagement.

Governance planning template for local survey collection

This template supports compliance with essential governance requirements for collecting new self-reported data within NSW Health.

Once completed, this local governance planning template should be:

- endorsed by an appropriately authorised group(s) with strategic and operational responsibility for local self-reported information survey collections
- added to a register of endorsed self-reported information survey collections
- audited regularly to ensure the collection continues to meet the requirements of this guide.

New collection details

Enter your response below

Name

What is the name of your collection?

Primary purpose(s)

What is the primary purpose of the data collection, why do we need this information? (e.g. supports clinical decision making, service improvement)

Secondary purpose

Will the data be able to be used for any other purposes? If so, what? (e.g., accreditation, benchmarking)

Consent or collection notices

What consent processes will be used? Provide copies of the consent form or collection notice.

Cohort(s)

What cohort(s) does your collection or survey target? (e.g., clinical stream such as diabetes, care setting (ED), age group such as 18–25-year-olds, survey stream such as rapid view, reflective, point of care, population view)

Collection methods

What methods will be used to collect the self-reported information? (e.g., online survey, paper-based survey, interviews, other: please specify)

Mode of collection

How will the data be collected? (e.g., HOPE, QARS or other electronic system, manually) If manually, how will the data be collated and stored?

Frequency of collection

How frequently will the survey be completed? (e.g. at discharge, six months following program completion)

Type of data being collected

Is the data Personally Identifiable Information (PII), Health Information, Aggregate Data, Free Text? If other, please specify

Duration of collection

Is this an ongoing or time-limited collection?

Roles and responsibilities

Data sponsor

Who oversees the strategic management, governance and operation of the data collection on behalf of the organisation including appointing a Data Custodian?

Data custodian

Who is responsible for the day-to-day management and oversight of the data from this collection? This person has the authority to approve access to the data, and the overall quality and security of the data.

New collection details

Enter your response below

Data steward

Who is responsible for the day-to-day operational management of the data collection, its completeness and quality? (i.e., this may be multiple people)

Approving local or state-wide governance committee

Please specify the approving committee

Data security, privacy and storage

Data storage

Where will the data be stored and ensured secure?

Data analysis

Will the data be analysed where it is stored? If not please specify what IT infrastructure the data will be analysed in and how it will be transferred to this location.

Personal and health information

Is there a process to review personal or health information that is collected to ensure that any such information that is not required anymore is disposed of or destroyed?

Data usage and sharing

Data access

Who are the intended user groups of the raw data? Who and how will access be granted to use the data?

Reporting and transparency of information

Where and to whom will the data be reported? (e.g., local and statewide governance committees including Board, clinical governance, annual strategic planning and consumer committees) Who will be accountable for taking action in response to the results? Is the data intended to be shared beyond the above groups?

Data linkage

Will the data be linkable (i.e., will it contain patient identifiers)? If so, how and why?

Data retention and deletion

Retention and deletion

What process is in place to ensure that any data that is not required anymore is archived, disposed of or destroyed in accordance with relevant policies and the State Records Act?

Registration of collection

Where will the collection be registered? How often will the collection be audited to ensure it continues to meet essential policy requirements?

New collection details

Enter your response below

Self-reported information principles

Person-centred

How are you ensuring the collection focuses on what matters most to patients, carers, families, communities and staff, and what is most useful for improving care?

Purposeful

How are you ensuring the collection produces meaningful insights and actionable data, and articulates how and by whom information will be used to improve outcomes, experiences and safety?

Governed

How are you ensuring the collection is resourced and governance plans are in place for collecting, reporting, sharing and responding to survey results to maximise their use and value?

Responsive

How are you ensuring that results and insights are used at the service level to improve care and shared across the health system to support continuous improvement?

Accessible

How are you ensuring the surveys and collection methods support participation by diverse populations and results are available to multiple audiences, including consumers?

Proportionate

How are you ensuring the data is collected once and used for multiple purposes to ensure the volume, frequency and duration of data collections minimise duplication and burden?

Validated

Is the collection based on well-established evidence and are collection tools fit for purpose?

Transparent

Is the collection accompanied by information on its purpose and how responses will be used?

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