

## Prevention and Response to Violence Abuse and Neglect, and Child, Youth and Families Data Governance

**Summary** This document outlines the roles and responsibilities involved in data governance, and the structures in place to ensure effective and consistent management of PARVAN and CYF data assets.

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# PREVENTION AND RESPONSE TO VIOLENCE ABUSE AND NEGLECT, AND CHILD, YOUTH AND FAMILIES DATA GOVERNANCE

## PURPOSE

The purpose of this document is to establish best practice guidelines for the governance of state wide data assets established in the areas of Prevention and Response to Violence, Abuse and Neglect Unit (PARVAN) and Child, Youth and Families (CYF) within the NSW Ministry of Health.

This document outlines the roles and responsibilities involved in data governance, and the structures in place to ensure effective and consistent management of PARVAN and CYF data assets.

This Guideline builds on the NSW Health Data Governance Framework (*GL2019\_002*) and intends to provide guidance to all key stakeholders on the implementation of this Framework in relation to PARVAN and CYF data assets. The NSW Ministry of Health will follow the identified escalation pathways in the creation, modification, retiring, and business-as-usual management of state wide data assets.

## KEY PRINCIPLES

Decisions made about data governance, data management, and information and communication technology (ICT) solutions should be compliant with the principles of data management for NSW Health, as outlined in the NSW Health Data Governance Framework. This includes principles on governance, collection, organisation, security, use, sharing and maintenance of data, to support the structured and consistent management of data assets.

All state wide data assets must have a data governance structure consistent with the NSW Health Data Governance Framework and the NSW Health delegations manuals.

## USE OF THE GUIDELINE

The NSW Ministry of Health and Chief Executives of NSW Districts / Networks and Pillar Organisations are responsible for the implementation of this Guideline within their services / facilities. This includes ensuring that local protocols or operating procedures are in place, are aligned and are consistent with this Guideline.

## REVISION HISTORY

Version	Approved by	Amendment notes
May-2019 (GL2019_006)	Deputy Secretary, Health System Strategy and Planning	New guideline providing a framework for the governance of PARVAN and CYF state wide data assets.

## ATTACHMENTS

1. Guideline - Prevention and Response to Violence Abuse and Neglect, and Child, Youth and Families Data Governance

**Prevention and Response to Violence Abuse and  
Neglect, and Child, Youth and Families Data  
Governance**



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**Issue date:** June-2019

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## Acronyms

CHeReL	Centre for Health Record Linkage
CHIRP	Community Health Information Reporting Project
CPH	Centre for Population Health
CYF	Child, Youth and Families
EDWARD	NSW Health Enterprise Data Warehouse
eMR	Electronic Medical Record
FTE	Full Time Equivalent
GRB	Government Relations Branch
HIPGC	Health Information and Performance Governance Committee
HRIP	Health Records and Information Privacy Act
HSPB	Health and Social Policy Branch
ICT	Information and Communication Technology
MH	Mental Health
OPERA	Operational Performance Enterprise Reporting Application
PARVAN	Prevention and Response to Violence, Abuse and Neglect
VAN	Violence, Abuse and Neglect

## 1 BACKGROUND

### 1.1 About this document

Data is one of NSW Health's most important strategic assets that is critical in enabling the health system to manage, monitor, improve and fund the services it delivers.

Effective governance of this data is essential in ensuring compliance with legal and regulatory obligations in acquiring, handling, storing and releasing data.

This guideline has been developed to support the establishment of data assets in the areas of Prevention and Response to Violence, Abuse and Neglect (PARVAN) and Child, Youth and Families (CYF) and to support implementation of the data governance processes outlined in the [NSW Health Data Governance Framework GL2019\\_002](#).

The purpose of this document is to provide reference to all staff involved in the collection, management and governance of PARVAN and CYF state wide data assets. This guideline intends to:

- Identify the roles and responsibilities of all staff involved in data governance for PARVAN and CYF state wide data assets;
- Support staff in working towards best practice in data governance and data management; and
- Establish clear processes for staff to ensure consistency in practice in relation to data governance, data management, and information technology governance to support PARVAN and CYF data requirements.

The roles and responsibilities of staff are further outlined in [Section 3.1.1](#).

### 1.2 Key definitions

#### 1.2.1 Definition: Data governance

*Data governance* designates the source of authority for making decisions about data, the roles/structures authorised to make decisions, and the basis upon which decisions are made.

#### 1.2.2 Definition: Data management

*Data management* is the planning, execution and oversight of policies and processes that acquire, store, protect, and deliver data and information assets.

#### 1.2.3 Definition: Disclosure

*Disclosure* refers to the release of data outside the NSW Ministry of Health. This includes release to Local Health Districts, Specialty Health Networks, interagency partners, universities, and all other organisations or individuals.

#### **1.2.4 Definition: Disclosure on a 'back to notifier' basis**

An organisation that has provided unit record data to the NSW Ministry of Health may request a copy of that information to be returned to them. This is called 'back to notifier' disclosure.

Unit record data may be returned to the original notifying agency without further approval, providing that the information returned does not contain additional personal information from another source. Enhancements to the unit record data such as grouping postcodes into health service areas are acceptable.

#### **1.2.5 Definition: Identified and de-identified data**

Within some NSW Health data collections, data may be classified in various ways such as: fully identified data, semi-identified data, re-identifiable data and de-identified data.

De-identified data or information is information or opinion about a person whose identity cannot be ascertained from the information or opinion.

When considering the implications under privacy law for the access, use or disclosure of health information held in any context within NSW Health, the definitions of "health information" and "personal information" used in the HRIP Act needs to be considered.

*Health Information* may include personal information or an opinion about the physical, mental health or disability status (at any time) of an individual, an individual's express wishes about the future provision of health services or a health service already provided, and other information which is collected to provide, or assist in providing a health service.

*Personal Information* means information about an individual whose identity is apparent or can reasonably be ascertained from the information or opinion.

If there is a reasonable chance that the information is potentially identifiable, it will fall within the ambit of the privacy law controls. Whether information can be considered de-identified will be dependent on the specific circumstances which arise in any disclosure. The HRIP Act only applies to personal health information.

#### **1.2.6 Definition: Information Technology governance**

*Information Technology governance* describes processes that ensure the effective and efficient use of Information Technology in enabling an organisation to achieve its goals.

#### **1.2.7 Definition: State wide data asset**

A *state wide data asset* is a data collection, data stream, or dataset, held by a NSW Health entity; including the Ministry of Health, Local Health Districts, Specialty Health Networks, Shared Services, Agencies and Pillars.

A data asset is within the scope of the NSW Health Data Governance Framework if it meets all of the following criteria:

- Holds all relevant information from across NSW Health entities;
- Is made up of patient, staff or workforce, organisation, or financial information; and
- Is mandated either by law or a policy recognised by NSW Health.



Data collections, data streams or datasets that do not meet the definition of a state wide data asset are not strictly governed by the NSW Health Data Governance Framework, or by these guidelines. However both the Framework and these guidelines represent a best practice approach and should be adhered to wherever possible.

### **1.2.8 Definition: Summary level data or aggregate data**

*Summary level data* or *aggregate data* refers to information that has been compiled into data summaries, typically for reporting purposes. This may include but is not limited to workforce FTE information, financial acquittals, and counts of service activity.

### **1.2.9 Definition: Unit record data and summary level or aggregated data**

*Unit record data* are electronic records of information that may relate to the health of an individual or individuals, staff or workforce, organisation, or financial information. Applications for the release of unit record data relating to the health of individuals must comply at minimum with the Policy Directive [PD2015\\_037 Disclosure of unit record data for research or management of health services](#).

## **1.3 Scope**

The scope of this document applies to state wide data assets relating to strategic or policy areas of PARVAN and CYF. This guideline intends to establish best practice in relation to non-clinical activities and functions in the governance of state wide data assets. This may include decisions on creating, modifying, retiring, and business-as-usual management of state wide data assets.

Health data may be obtained as a by-product of clinical care. This document does not include guidelines on documentation and management of client information that is gathered, recorded, and stored for clinical purposes. Services should refer to the NSW Health Policy Directive on [Health Care Records - Documentation and Management](#) and any other relevant Clinical Policies and Procedures that relate to specific services.

## **1.4 Legal and legislative framework**

This guideline has been prepared in order to meet the requirements of the NSW Health Data Governance Framework, which is subject to compliance with relevant statutes, regulations and policies, including the NSW Health Code of Conduct.

Obligations regarding data governance arise from State and Commonwealth statutes including:

- *Government Information (Public Access) Act 2009* (NSW)
- *Health Records and Information Privacy Act 2002* (NSW)
- *Health Administration Act 1982* (NSW)
- *Higher Education Support Act 2003* (Cth)
- *Higher Education Standards Framework (Threshold Standards) 2015* (Cth)
- *Mental Health Act 2007* (NSW)
- *Privacy Act 1988* (Cth)

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- *Privacy and Personal Information Protection Act 1998* (NSW)
  - *Public Health Act 2010* (NSW)
  - *State Records Act 1998* (NSW)

NSW Health also has common law obligations in relation to information obtained as part of the treating relationship.

Data governance roles specified in this document are also subject to the:

- NSW Health Combined Administrative Financial Staff Delegations Manual
- Health System Support Group Delegations Manual
- HealthShare NSW Delegations Manual
- Health Infrastructure Delegations Manual
- District, Network or Pillar Delegations Manual

## 2 CONTEXT

### 2.1 Why does PARVAN and CYF require a consistent approach towards data governance?

#### 2.1.1 Intersecting strategic priorities and frameworks

The health, safety and wellbeing of children, young people and families and the health impacts of violence, abuse and neglect have significant intersections. An integrated public health approach recognises that people may enter the NSW Health system at numerous points, requiring multiple interventions from a range of service providers.

The data system, analytics and reporting requirements across these portfolio areas are underpinned by a number of relevant strategic priorities outlined below.

#### **Portfolio specific strategic priorities and frameworks:**

- Premiers and Ministerial priorities
  - The work of PARVAN and CYF aligns with four of the twelve Premier's priorities including protecting our kids, reducing domestic violence reoffending, tackling childhood obesity, and young people in specialist homelessness services.
- Whole of Government Reforms
  - A number of reporting requirements are emerging as a result of the NSW Government's response to the Royal Commission into Institutional Responses to Child Sexual Abuse, and other cross government initiatives including Their Futures Matter reforms, NSW Sexual Assault Strategy, NSW Ombudsman's review of the Joint Investigation Response Team Partnership, and NSW Domestic and Family Violence Blueprint for Reform 2016-2021.
- The First 2000 Days Framework
- Integrated Prevention and Response to Violence, Abuse and Neglect Framework
- Healthy Safe and Well: A Strategic Health Plan for Children, Young People and Families 2014-24
- NSW Youth Health Framework 2017 - 2024

#### **Broader NSW Health strategic priorities and frameworks:**

- NSW Health Strategic Priorities
  - Strategy 3: Integrate systems to deliver truly connected care
  - Strategy 6: Enable eHealth, Health Information and Data Analytics
- NSW Health Analytics Framework
- NSW Health Data Governance Framework

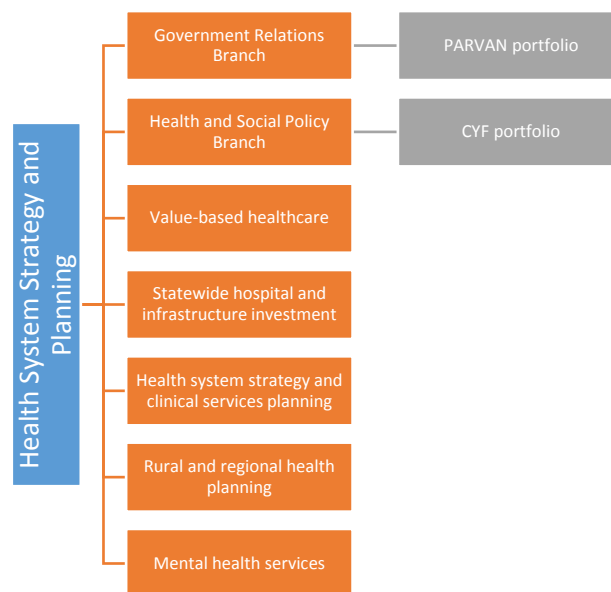
Given these intersections and likely overlaps in client groups accessing services and programs managed by PARVAN and CYF, it is pertinent that data governance over these areas are brought into alignment to ensure coordinated strategic oversight and direction.

### 2.1.2 Divisional accountabilities

The Ministry of Health’s Government Relations Branch and Health and Social Policy Branch provides strategic and policy leadership, and acts as systems manager across a number of portfolio areas relating to PARVAN and CYF including:

- Health services and programs to respond to violence, abuse and neglect.
- Health responses, services and programs to promote the health and wellbeing of mothers, babies, children and young people.
- Support for hospital care (including outreach) of infants, children and young people.

The Government Relations Branch and Health and Social Policy Branch are both within the Health System Strategy and Planning Division at the Ministry of Health. The portfolios relating to PARVAN and CYF may be operationally managed across various business units within these branches.



*Figure 1: Health System Strategy and Planning Divisional accountabilities*

## 2.2 Current state program level data sets

There are currently a number of siloed data collections at a service and/or program level in both unit level and aggregated form across PARVAN and CYF portfolio areas. These include data collections for the following areas:

PARVAN data collections	CYF data collections
<ul style="list-style-type: none"> <li>Sexual Assault Services</li> <li>Joint Child Protection Response Program</li> <li>Child Protection Counselling Services</li> <li>Family Referral Services</li> <li>Domestic Violence Routine Screening</li> <li>New Street Services</li> </ul> <p>In development:</p> <ul style="list-style-type: none"> <li>Child Protection Units/Teams</li> <li>Aboriginal Family Wellbeing and Violence Prevention Strategy</li> </ul>	<ul style="list-style-type: none"> <li>Child and Family Health</li> <li>Sustaining NSW Families</li> <li>Out of Home Care Health Pathway</li> <li>Universal Health Home Visiting</li> <li>Building Strong Foundations for Aboriginal Children, Families and Communities</li> <li>State-wide Infant Screening Hearing – (SWISH) Screening</li> <li>State-wide Infant Screening Hearing – (SWISH) Diagnostics</li> <li>State-wide Eyesight for Pre-Schoolers – (STEPS) Screening</li> <li>State-wide Eyesight for Pre-Schoolers, Paediatric Ophthalmic Outpatient Clinics</li> <li>Perinatal Data Collection</li> <li>Families NSW (including SAFE START)</li> <li>Aboriginal Maternal and Infant Health Service Data Collection</li> </ul>

Table 1: Existing PARVAN and CYF data collections

The Ministry of Health have previously been using both ad-hoc and routine analytics processes to fulfil business reporting requirements for these data collections.

### 2.3 Data Systems and Analytics Roadmap Implementation

PARVAN and CYF are undertaking a joint Data Systems and Analytics Roadmap Implementation Project to achieve a goal state architecture, following a strategic review conducted in 2017. Within the roadmap, PARVAN and CYF are taking an incremental approach to transition from the current state of siloed and ad-hoc data collections towards the goal state data architecture.

The **goal state** architecture is a longer-term goal for the information required for regular PARVAN and CYF monitoring and reporting to be fully delivered through the NSW Health Enterprise Data Warehouse (EDWARD). To achieve this goal state, the PARVAN and CYF reporting and analytics requirements which take priority need to be further defined, in order to rationalise the current siloed service and program level datasets across both units. There are three state wide minimum data sets planned:

- Violence, Abuse and Neglect Minimum Data Set
- Domestic Violence Routine Screening Minimum Data Set
- Child, Youth and Families Minimum Data Set

The **transitional** architecture uses EDWARD to the greatest extent possible in the interim. This includes exploring the capacity to access the existing core Non Admitted

Patient and Perinatal datasets, as well as retaining the use of the current siloed datasets to fulfil a basic level of reporting and analytics requirements. In the longer term, the transitional architecture is expected to be retired once the goal state architecture has been implemented.

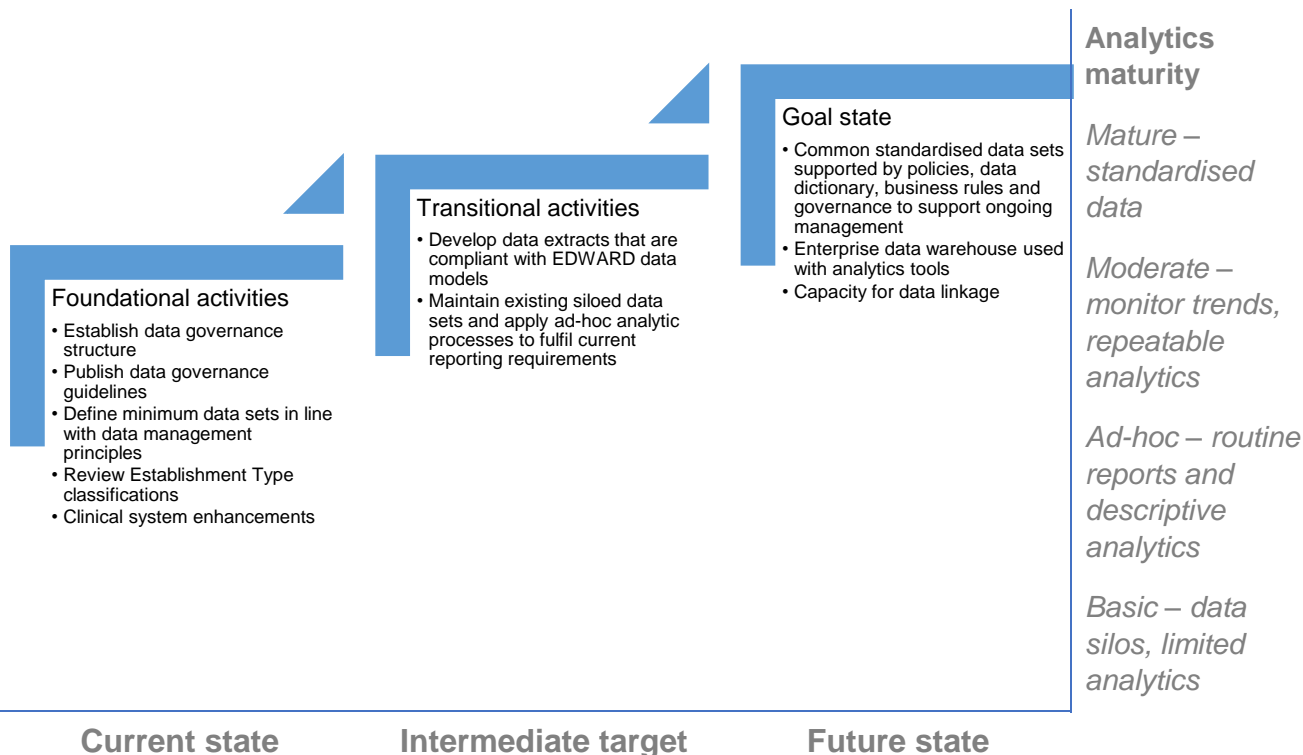


Figure 2: PARVAN and CYF Data Systems and Analytics Roadmap

Further state wide data assets that may be established to meet business requirements should also refer to these guidelines.

### 3 PRINCIPLES OF DATA MANAGEMENT

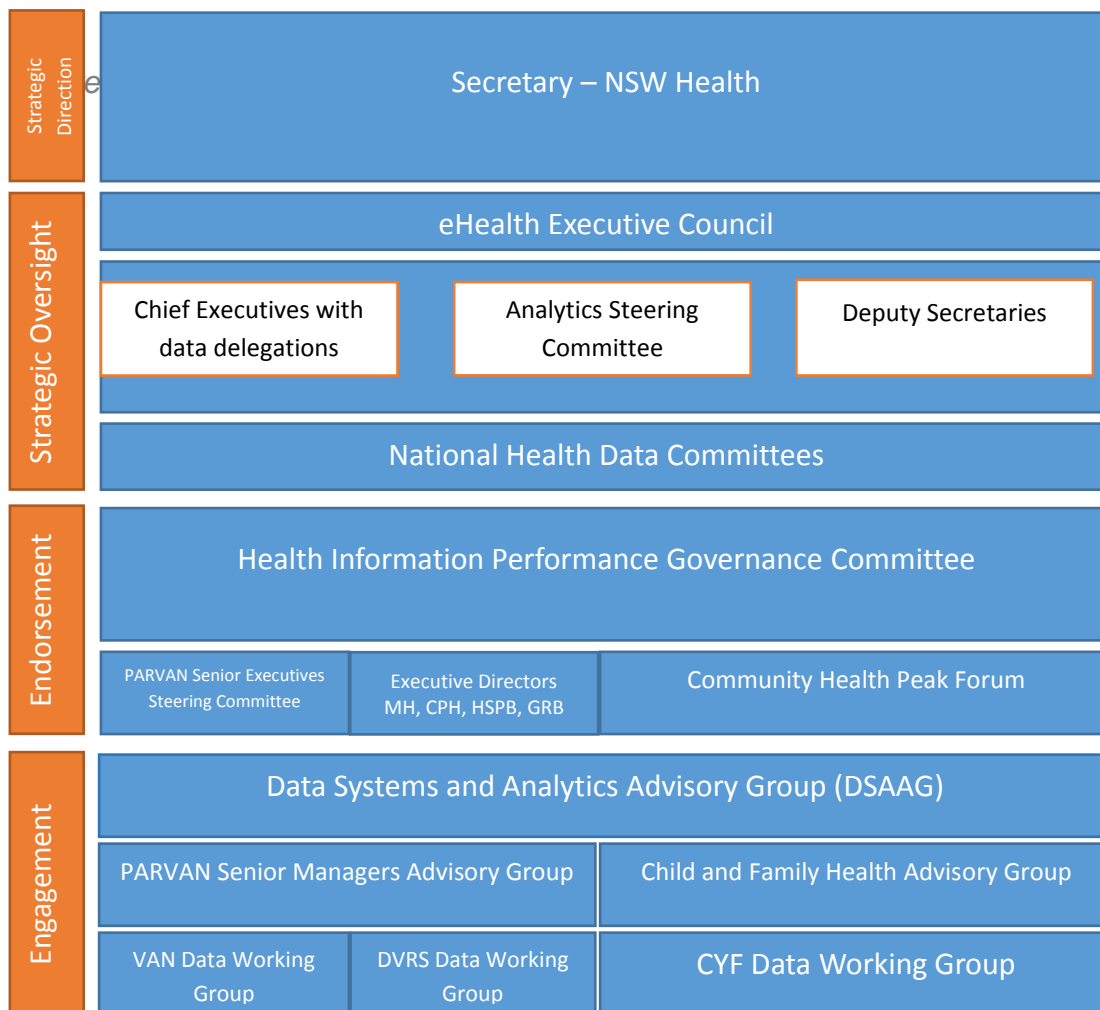
Decisions made about PARVAN and CYF data assets should be guided by the following data management principles adapted from the NSW Health Data Governance Framework and NSW Information Management Framework.

- **Governance:** Data is managed in a transparent and accountable manner, is compliant with relevant legislation and policies, and has clearly identified data governance roles and responsibilities.
- **Collection:** Data is collected by the NSW Ministry of Health to facilitate health service delivery and support its functions as system manager. Data collection burden should be minimised wherever possible, following the principle of ‘collect once and use multiple times’.
- **Organisation:** Data is managed in repositories so it is accessible and there is a single source of truth. Data is compliant with published metadata standards.
- **Security:** Data is protected against unauthorised access, alteration, loss or deletion, and there are auditable processes in place that demonstrate protection of sensitive data and information.
- **Use:** Data is used to support planning, evidence based policy development, decision making, resource allocation, reporting and communication at all levels of the health system. Where appropriate, reports are published to ensure public accountability and transparency in the health system.
- **Sharing:** Data is accessed by NSW Health personnel with a legitimate purpose to accessing the information. The privacy and confidentiality of NSW citizens and NSW health services is respected and compliant with all relevant state and commonwealth legislation, the NSW Health delegations manual, and any other relevant statutory delegations.
- **Maintenance:** Data is available and reliable, and there are processes to ensure information collected and held by NSW Health remains current and fit for purpose.

### 3.1 How will PARVAN and CYF implement these principles?

#### 3.1.1 Foundational activity 1: Establish PARVAN and CYF Data Governance Structure

A Data Governance structure with clearly identified roles and responsibilities is being established to manage PARVAN and CYF data assets. The data governance structure within the broader context of the NSW Health data governance framework is shown in Figure 3.





*Roles specific to supporting PARVAN and CYF data governance:*

### **Data Sponsor**

The Deputy Secretary, Health System Strategy and Planning will provide executive sponsorship for the establishment of any new state wide data assets managed by these business units. Key accountabilities of the Data Sponsor may include:

- Establishing the basis for the asset
- Provide strategic oversight and authorise appropriate resources for the management of the asset
- Implement a data governance framework for the asset
- Authorise any public release of information, except where this is delegated by the Combined NSW Health Delegations Manual

### **Data Custodians**

The Data Sponsor will appoint the Executive Directors of the Government Relations Branch, and Health and Social Policy Branch respectively to be the Data Custodians for any new state wide data assets established by these units. Data Custodians provide approval for access to the data, and oversee the quality and security of the data asset. This may include approvals for Ministry of Health staff to access through EDWARD. Key accountabilities of the Data Custodians may include ensuring:

- There are published policy directives and/or information bulletins outlining the purpose of the asset.
- The asset has published metadata, including a data dictionary, business rules and guide for use.
- Use of the data aligns with the purpose for which it was collected.
- The asset remains relevant to system and business needs.
- Processes are in place to provide feedback to data suppliers about data quality.
- Processes are in place to respond to breaches and potential breaches of data security, and the data asset's policies and procedures.
- Material risks and issues are escalated to the Data Sponsor.

### **Data Stewards**

The Data Custodian will appoint the appropriate resources to be Data Stewards for its state wide data assets. The Data Stewards are responsible for the day to day management and operation of the data asset, its completeness and quality. Key accountabilities may include:

- Managing the data asset in compliance with relevant legislation, policies and standards.
- Developing a policy directive and/or information bulletin for the asset.
- Ensuring there are up to date technical documents for the supply and storage of the data.
- Working with stakeholders to develop and maintain metadata including a data dictionary, business rules and guide for use.
- Coordinating stakeholder engagement and input into the business requirements for the data asset, including any stakeholder working groups to help manage the asset.
- Providing feedback to data suppliers in relation to data quality issues

- Providing advice to the Data Custodian and Data Sponsor on the management of the asset as required.
- Escalating material risks and issues to the Data Custodian.

### **Data asset working groups**

Data working groups will be established to assist with the development and ongoing management of PARVAN and CYF data assets. Currently the following new working groups are planned to support the development of three distinct data assets:

- Violence, Abuse and Neglect Data Working Group
- Domestic Violence Routine Screening Data Working Group
- Child, Youth and Families Data Working Group

These datasets are envisaged to be extensions to the existing core NSW Health non-admitted patient data collection for service activities delivered in the non-admitted setting.

The purpose of these working groups are to:

- Provide opportunities for stakeholder engagement.
- Provide advice to the Data Steward in relation to data asset policies and procedures.
- Review proposals for modifications to the asset and provide advice.
- Progress work plan items that support the objectives and strategic direction set out by the Data Sponsor and Data Custodian.
- Provide opportunities for consultation and engagement with Non-Admitted Patient Data Coordinators where subject matter specific advice is required.
- Escalate material risks and issues to relevant Data Governance Committees and Executive Committees.

As the state wide data assets enter into business-as-usual arrangements, the data working groups will provide an ongoing advisory role in the management of the data asset. Membership on the working group may change as required over different phases of a project in establishing a new state wide data asset. Member representation should cover subject matter expertise in both clinical content areas and data and clinical information management.

### **Other advisory groups and committees:**

Matters requiring further **advice** may be escalated to other existing advisory groups including:

#### **Data Systems and Analytics Advisory Group**

Provides strategic advice on matters related to data systems, analytics, management and governance that are relevant to PARVAN and CYF. This may include but is not limited to advice on the development of state wide data assets, data provision mechanisms, warehousing, and reporting solutions.

## **Prevention and Response to Violence, Abuse and Neglect Senior Managers Advisory Group**

The Prevention and Response to Violence, Abuse and Neglect Senior Managers Advisory Group provides strategic policy and system reform advice to the Prevention and Response to Violence, Abuse and Neglect Senior Executives Steering Committee. The members have senior managerial oversight of the violence, abuse and neglect specialist services. This group is to escalate governance related matters to the PARVAN Senior Executives Steering Committee for decisions and resolution. Such matters include strategic policy, service issues, data & performance reporting, risk management, workforce, VAN implementation & planning.

## **Child and Family Health Advisory Group**

The Child and Family Health Advisory Group provides a forum for discussion and advice on strategic action to support achievement of the child and family health related aspects of the *Healthy, Safe and Well: Strategic Health Plan for Children, Young People and Families of NSW 2014-2024*. The scope of the Child and Family Health Advisory Group includes the health and wellbeing of children and their families, and will complement the scope of the Youth Health and Wellbeing Advisory Group.

### *Other data advisory groups*

PARVAN and CYF may also consult and engage with other existing data advisory or working groups and data custodians where matters are relevant to other data streams. This may include but is not limited to:

- Non Admitted Patient Data Collection Working Group
- Drug and Alcohol Data Coordinators Working Group
- Mental Health Information Management Meeting
- Allied Health Data Working Group
- Maternity Information Systems Advisory Group
- Admitted Patient Data Collection Working Group
- Emergency Department Data Collection Working Group
- Patient Reported Measures Implementation Advisory Committee

Matters requiring further **endorsement** may be escalated to the following existing committees or roles:

## **Prevention and Response to Violence, Abuse and Neglect Senior Executives Steering Committee**

The Prevention and Response to Violence, Abuse and Neglect Senior Executives Steering Committee members are Tier 2/3 Directors and Managers of districts and networks, and provide strategic policy direction and system reform advice. The members have strategic oversight of the violence, abuse and neglect specialist services in their

district, and decision-making capacity in relation to local health service planning and workforce development in order to ensure their district/network is equipped to meet the needs of children, young people and families who have experienced violence, abuse and neglect.

### **Community Health Peak Forum**

The Community Health Peak Forum provides leadership, direction, and support and acts as a collaborative resource for the development and effective management of community health services in the NSW Health system. This includes Child, Family and Youth Health Services. Members include Directors of Community Health or equivalent for districts and networks.

### **Executive Directors – Health and Social Policy, Mental Health, Centre for Population Health, Government Relations**

The Domestic Violence Routine Screening Program is currently delivered by Maternity, Child and Family Health, Mental Health, and Drug and Alcohol services, with the PARVAN Unit as the policy lead. The Executive Directors of the respective service areas at the Ministry of Health will act as a point of escalation and decision making for this data asset.

*Groups and committees that support NSW Health data governance more broadly:*

#### **Health Information Performance Governance Committee**

The Health Information and Performance Governance Committee (HIPGC) is the principal Data Governance Committee in NSW Health.

The role of HIPGC is to advise on matters relating to data governance including aspects of information management, performance reporting development, digital health (eHealth), governance and strategies, and to facilitate collaboration between the Ministry of Health, Pillars, Shared Services and districts and networks. HIPGC provides advice to the following:

- Deputy Secretary, Patient Experience and System Performance
- Deputy Secretary, People, Culture and Governance
- eHealth Chief Executive/Chief Information Officer
- NSW Health Analytics Steering Committee
- Secretary, NSW Health

HIPGC may advise on matters including but not limited to:

- State data collection and reporting requirements, with a view to rationalising, consolidating and minimising current and future data requirements in addition to maximising the efficiency and effectiveness of data and information collection and use across NSW Health.
- State data collection management, including data provision mechanisms, the flow of information and its custodianship, management; and use in the relevant state data warehouses, reports and dashboards.

HIPGC also contributes to the development of data standards for inclusion in NSW Health Information Resource Directory (HIRD), including alignment to national standards.

PARVAN and CYF will have nominated representative(s) on this Committee, who shall have sufficient authority for decisions or commitments on behalf of both units.

HIPGC may seek guidance or report the outcome of deliberations to the following:

### **National Health Data Committees**

National Health Data Committees are responsible for developing and setting national health minimum data sets and data standards. Such committees may include the National Health Information Standards and Statistics Committee, or the National Health Information and Performance Principal Committee.

### **NSW Health Analytics Steering Committee**

The NSW Health Analytics Steering Committee is responsible for driving implementation of the Analytics Framework across NSW Health. This committee may refer items to HIPGC regarding the progress of actions allocated in relation to the NSW Health Analytics Framework. The committee reports directly to the eHealth Executive Council.

### **eHealth Executive Council**

The eHealth Executive Council is the peak ICT committee for NSW Health. It directs the eHealth strategy, priorities and policy, oversees the implementation of the strategy and monitors use of ICT across the health system. The eHealth Executive council makes decisions in all ICT procurements/projects with an impact on customers, and new proposals to undertake significant ICT business activities.

*Responsibilities of other key stakeholders:*

### **NSW Ministry of Health, Pillars and eHealth NSW**

The NSW Ministry of Health will provide data sponsorship, custodianship and stewardship of state wide data assets. PARVAN and CYF will work with Pillars and eHealth NSW to ensure alignment of data and IT governance.

### **Local Health Districts/Specialty Health Networks**

Districts and networks that supply data are responsible for ensuring compliance with all relevant legislation, policies and guidelines relating to data collection. Districts and networks should provide a timely response to any issues and matters raised by the Data Custodian or Data Steward, and inform them of any local issues that may impact on data quality and integrity.

## Data users

All data users are responsible for ensuring that data is recorded or collected according to data standards. Staff must abide by all relevant legislation, policies and standards, including the NSW Health Code of Conduct, and all terms and conditions associated with approval for access to data.

Such terms and conditions may include acknowledgement that:

- The use of data is monitored and auditable. There are criminal offences relating to the unauthorised use and misuse of electronic data in the *Crimes Act 1900*.
- Use and disclosure of health information of patients should only be for purposes directly relevant to the staff's role and for other purposes that would be reasonably expected as relevant to their role,
- Users are responsible at all times for appropriate use of user logins and passwords.
- Users are required to advise their line managers as soon as they become aware of any breaches of security or privacy of information.

### 3.1.2 Foundational activity 2: Publish the Data Management Guidelines through the Policy Distribution System

NSW Health policy directives, guidelines and information bulletins are issued and controlled through the Policy Distribution System.

The establishment of this document as a Guideline Policy Document is to ensure transparency to all key stakeholders involved and their expected roles and responsibilities in adhering to best practice, with the intention that it is adopted across NSW Health Organisations.

NSW Health Organisations must ensure that sound reasons exist for departing from recommended standards or practices within a guideline issued through the Policy Distribution System.

### 3.1.3 Foundational activity 3: Ensure proposed state wide data assets are compliant with the principles of data management

PARVAN and CYF will be guided by the principles of data management outlined in the NSW Health Data Governance Framework when developing its data assets.

- **Governance:** A data governance structure will be established as outlined in [Section 3.1.1](#).
- **Collection:**
  - There are a number of high level data requirements to enable PARVAN and CYF to fulfil their core functions as system, program and service managers and to support service delivery. In reviewing the proposed minimum data sets, each data element must have a justification for collection to meet specific business requirements.

- PARVAN and CYF will work with the System Information and Analytics Branch in the Ministry of Health to ensure data standards are compliant with existing metadata standards.
- PARVAN and CYF will aim to minimise collection burden for clinicians by streamlining data collection processes with existing clinical workflows so that data collected is largely a bi-product of service delivery through mainstream clinical systems.
- As an over-riding principle, any client data collected should be essential to the clinical care of the individual, and not pose an unreasonable burden on clinicians.
- Similarly, clinical data should not be included in extracts for a statewide repository unless there is a defined requirement for this data for authorised secondary purposes that support the functions set out in the Health Services Act 1997.

Any additional data that may be considered for collection must meet the legislative and policy requirements of:

The Health Records and Information Privacy Act 2002, in particular:

**Health Privacy Principle 2:** Collection and information sought must be relevant, not excessive, accurate and not intrusive.

Information should only be collected if:

- The purpose is related to care and treatment, if it is directly related to the functions of NSW Health, and collection is essential to perform these functions
- The information collected is clinically necessary, is not excessive and is accurate, up to date and complete
- Collection does not unreasonably intrude on the personal affairs of the individual

**Health Privacy Principle 3:** Collection from individual concerned.

Information must be collected from the person it relates to, unless it is unreasonable or impractical to do so, and the information is essential to provision of the health service.

Records should only include personal information about people other than the client when this information is necessary for the care and treatment of the client.

- **Organisation:** The goal state data architecture for PARVAN and CYF identifies EDWARD as the main repository for storing and managing data so there is a single source of truth. PARVAN and CYF will ensure there are policy directives or information bulletins on data collection requirements to support consistent application of business rules.
- **Security:** All personnel have a responsibility in maintaining the security and protection of data against unauthorised access, alteration, loss or deletion. Any systems used must demonstrate that there are auditable processes to protect sensitive data and information.

- **Privacy:**

- Personal health information (i.e. identifiable patient data) held by NSW Health is protected by privacy legislation, the NSW Health Records and Information Privacy Act 2002. The NSW Health Privacy Manual for Health Information provides guidance to staff on how to comply with this legislation and provides practical examples.
- Our obligation to inform patients/clients of the use of their health information is provisioned by the NSW Health Privacy Leaflet for Patients (Appendix 5 of the Privacy Manual).
  - “Use or disclosure of Information – Your personal health information held either in paper or electronic format may be used by the NSW public health service, or disclosed outside the health service, to enable appropriate care and treatment to be provided to you. For example, your information may be used or disclosed for purposes relating to the operation of the NSW health service and treatment of our patients, including funding, planning, safety and quality improvement activities.”
- Section 11.2.1.1 of the NSW Health Privacy Manual for Health Information also provides common examples of exemptions to use and disclosure of information for a directly related purpose, including for health service planning and quality improvement activities.

- **Confidentiality:**

All NSW Health staff are bound by the code of conduct and various other instruments including the Privacy Manual. Confidentiality and privacy obligations extend to all Health workers in relation to patient information. Further IT system safeguards as recommended risk mitigation strategies:

- Staff education
- Acknowledgement on the system that staff are aware that highly sensitive information is stored on the database
- Only relevant staff should be able to access
- Security and audit processes

Any third party vendors contracted by NSW Health who have access to any of our data should sign a confidentiality agreement (to be signed by individual employees and subcontractors). See [Attachment 1](#) for the Confidentiality Agreement for Vendor Staff template.



- **Use:** PARVAN and CYF may use data collected to fulfil the following core functions:

PARVAN and CYF Core Functions	Data Requirements
<ul style="list-style-type: none"> <li>• Statewide service planning and evaluation</li> <li>• Monitoring and improving the effectiveness and efficiency of programs and services</li> <li>• Setting clinical policy</li> <li>• Assessing needs of priority populations</li> <li>• Ensuring funding is used as intended</li> <li>• Supporting information and research activities</li> <li>• Collaborating with partner agencies to provide integrated care</li> <li>• Reporting on programs and responding to ad-hoc data requests (e.g. Ministerials)</li> </ul>	<ul style="list-style-type: none"> <li>• Information on performance of services</li> <li>• Information on access to services and equity</li> <li>• Information on service utilisation</li> <li>• Information on outcomes</li> <li>• Information on cost of services</li> <li>• Information on effectiveness of programs</li> <li>• Benchmarking performance</li> </ul>

- The use of personal health information for these purposes are provisioned under Health Privacy Principles 10 and 11 outlined in the Health Records and Information Privacy Act 2002, as they align with examples given for ‘directly related purpose’ exemptions, or meet the criteria for a ‘secondary purpose’ as a management or research activity. The use of personal health information must also be in accordance with guidelines, if any, as issued by the Privacy Commissioner.

**Health Privacy Principle 10:** Limits on use of personal health information.

Personal health information can be used for the purpose for which it was collected, or for other purposes recognised by the Act. These include a “secondary purpose” such as where there is consent for the use, the use is a “directly related purpose”, for management, training and research activities, for investigation and law enforcement, or where there are serious threats to individuals or the public.

**Health Privacy Principle 11:** Limits on disclosure of personal health information.

The provisions for disclosure of personal health information are the same as those for use of this information. They also include a provision that a person’s personal health information may be disclosed to immediate family members for compassionate reasons, provided that this is not contrary to the expressed wish of the individual.

- **Sharing:** Data is accessed by NSW Health personnel with a legitimate purpose to accessing the information. The privacy and confidentiality of NSW citizens and NSW Health services is respected and compliant with all relevant state and Commonwealth legislation, the NSW Health delegations manual, and any other relevant statutory delegations. Refer to [Section 4.5](#) for further processes for releasing data.
- Where appropriate, PARVAN and CYF may publish reports to ensure public accountability and transparency in the health system, as well as contributing to the evidence base to support policy development and health planning. This will also align more broadly with the 'open data principle' described in the NSW Government's Information Management Framework whereby information may be publically accessible or shared within and between organisations to improve services, planning and innovation, while ensuring governance processes are in place to protect personal and sensitive information.
- **Maintenance:** Data is available and reliable, and there are processes to ensure that information collected and held by NSW Health remains current and fit for purpose.  
PARVAN and CYF will maintain the data asset working groups for business-as-usual management. These groups may be convened to review proposals for modifying the data assets, and data quality.

#### **3.1.4 Foundational activity 4: Review non-admitted service unit establishment type classifications and related policies**

The following policy documents are relevant pre-requisites for standardising statewide reporting from a service provider perspective:

- [Registration of NSW Health Establishments](#)

This Policy Directive describes the mandatory requirement to register health establishment locations and service units within NSW, and record the registration details in NSW Health's, Health Establishment Registration Online (HERO) and release an extract to HealthDirect Australia to populate the National Health Service Directory.

- [Individual Service Provider Data Stream](#)

Outlines the data elements and classifications for collection, as represented within the ISP Shared Dimensions of the Enterprise Data Warehouse (EDW).

- [Non-Admitted Patient Establishment Type Definitions Manual](#)

The Establishment Type classification provides detailed information on non-admitted patient services provided by NSW Health. NSW Health Establishment Types are mapped to a Tier 2 class for the purposes of reporting to the Commonwealth and National ABF and costing.

PARVAN and CYF will undertake a review of service unit establishment types being used by service providers for which they have portfolio responsibility to ensure the

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Establishment Type Classification Principles are applied appropriately. This will also ensure there is clarity on which service providers are within scope to collect and report the minimum data sets created by these units.

### **3.1.5 Foundational activity 5: Clinical source system changes and enhancements for Violence, Abuse and Neglect services**

PARVAN have submitted an initiative brief to eHealth for clinical system enhancements to support the redesign of violence, abuse and neglect services and implementation of the Integrated Prevention and Response to Violence, Abuse and Neglect Framework. The intent is to develop a State Based design that is fit for purpose for both clinical and data collection and reporting requirements.

The prioritisation process occurs across a series of stages, designed to assess the strategic alignment and feasibility of the proposal. Refer to [Section 4.4](#) for further details on the eHealth's ICT Investment Assurance & Prioritisation process.

## **4 PROCESSES**

### **4.1 Creating a new state wide data asset**

The processes for creating a new state wide data asset are outlined in the NSW Health Data Governance Framework as follows:

#### **4.1.1 Development of a business case**

The business case should outline the potential benefits to the health system, projected costs and resource requirements and operational impact. Data Sponsors, Custodians, and Stewards must be identified and a working group established as required.

#### **4.1.2 Pilot testing**

The pilot should test the business and technical processes supporting the data asset, include appropriate project planning, and involve relevant ICT stakeholders. The pilot should validate that the data meets business requirements and allows for the refinement of metadata, supporting resources, and data management processes.

#### **4.1.3 Decision to proceed**

At the conclusion of the pilot, the Data Sponsor and other relevant stakeholders must decide whether to proceed to state wide implementation.

#### **4.1.4 Implementation plan**

A project implementation plan should provide detailed explanation of the roles and responsibilities, ongoing resources, processes for collection, reporting, storage and access to data, and custodianship. This should include development of ICT solutions and engagement with eHealth and other relevant ICT stakeholders.

#### **4.1.5 Implementation**

Metadata including a data dictionary, business rules and guide for use should be published, along with any necessary amendments to the combined NSW Delegations Manual. The final step is to complete the transition to a business-as-usual data governance model.

### **4.2 Modifying a state wide data asset**

On occasion it will be necessary to modify PARVAN and CYF data assets. This may occur in response to changes in clinical care, service delivery, strategic or system management priorities. A proposal to modify a state wide asset should ensure the following checklist is fulfilled:

- Identify the strategic or policy requirement for change.
- Consult with stakeholders (including Data Steward, Clinical and Data Advisory Groups, eHealth) to develop and specify the change and likely impact.
- Develop an implementation plan considering projected impact, any necessary changes to metadata, communication to relevant stakeholders (including data users), delegations, governance of the data asset, and resourcing.

- Seek endorsement of change request from the relevant governance committees (e.g. HIPGC, PARVAN Senior Executives Committee, Community Health Peak Forum).
- Seek approval from Data Custodian, and Data Sponsor.
- Publication of updated metadata including a data dictionary, business rules and guide for use, and communication of changes to relevant stakeholders.

### **4.3 Retiring a state wide data asset**

The retirement of a state wide data asset must be approved by the Data Sponsor with responsibility for the data asset. A proposal to retire a state wide asset should consider the following:

- Identify strategic or policy rationale for retirement, including why the asset is no longer required and specify alternative data sources if applicable.
- Consultation with stakeholders (including data users) to consider the impact.
- Plans for continued storage and maintenance or disposal of existing data.
- Re-deployment of data asset resources as required.
- Plans for repeal or amendment of any relevant asset-specific delegations.
- Formal rescission of relevant governance instruments and communication to all data users.

### **4.4 Clinical source system change requests and enhancements**

The Initiative Prioritisation Process has been developed by eHealth so that there is a standardised and transparent procedure to manage and evaluate ideas proposed by all stakeholder groups for ICT solutions within NSW Health. The Prioritisation Process applies to:

- Requests for funding for any initiatives that are enabled by eHealth.
- Situations that require re-prioritisation of projects on the forward program.
- Requests for significant change to in flight projects that are outside the scope of project change control processes.
- Local initiatives that are not seeking eHealth/capital funding but which do require implementation support from eHealth.

There are 3 steps to the process as shown below. Note that steps 1 and 2 can occur with a single submission if enough information is provided for an assessment to be made in the first proposal submitted.

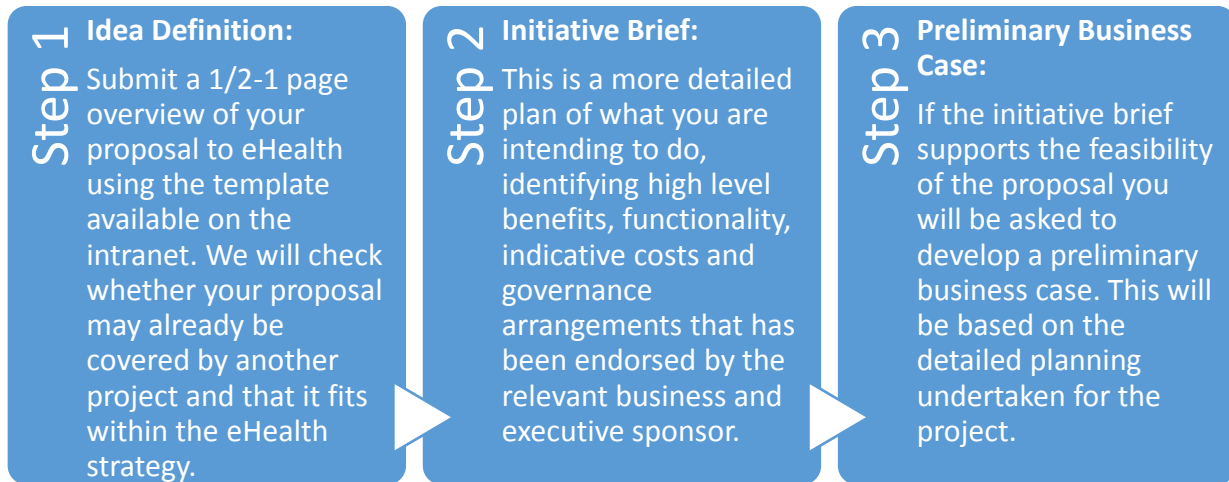


Figure 4: Initiative Prioritisation Steps

The Initiative Brief template can be found at [Attachment 2](#). New ICT initiatives requiring eHealth NSW delivery or oversight should be escalated to the Ministry of Health's ICT Governance Committee for review, prioritisation and approval via the Divisional or Branch representative(s) prior to submission to eHealth.

Following submission to eHealth, some key criteria for consideration through this process are:

- Alignment with premiers' priorities and other NSW Government Strategies
- Alignment with MoH priorities
- Executive endorsement (e.g. LHD Chief Executives, Ministry of Health Deputy Secretaries)
- Risk profile
- Benefits to patients
- Funding availability and approval
- If the project is set up for success (e.g. stakeholder engagement)

All proposals are prioritised in the same way, however projects that are found to be feasible and high priority are divided into two categories:

- **Fast tracked proposals** – projects that have a total estimated cost of less than \$250,000 can be approved for funding through eHealth's Innovation Fund. The approval process for these projects will end with the preliminary business case. Funding will be recommended by the Innovation, Strategy and Architecture team at eHealth and can be approved by the Chief Executive, eHealth to be allocated immediately. These projects will then work with the relevant portfolio to commence implementation planning.

- **Major strategic projects** – projects that exceed the cap for innovation funding will be endorsed by the eHealth Executive Council and recommended to the Ministry of Health for inclusion in the Asset Strategy for capital funding. These projects will need to have detailed business cases developed to meet the Department of Finance, Services and Innovation (DFSI) requirements and will be subject to the DFSI gateway process.

#### **4.4.1 New data items and functionality**

This work needs to be submitted and prioritised with eHealth via their ICT Investment Assurance & Prioritisation process.

#### **4.4.2 Changes to existing data elements**

The existing eHealth State Based Build Application Advisory Group process, is used for requesting changes to existing functionality in the Cerner eMR only.

### **4.5 Requests to release data**

#### **4.5.1 Process for disclosure of unit record data**

The following process for disclosure of unit record data is described in the Policy Directive [PD2015\\_037 Disclosure of unit record data for research or management of health services](#).

All requests for disclosure of unit record data other than on a ‘back to notifier’ basis, or disclosures made under a contractual arrangement, should follow the procedure described below:

The data custodian should consider:

- Whether aggregate data would be sufficient to meet the needs of the person making the request.
- Whether the request should be refused. Examples of reasonable grounds for refusal may include:
  - I. There is no legal basis for the disclosure
  - II. There is insufficient security for the data to be stored
  - III. The organisation/person requesting the data does not have sufficient experience to reasonably be able to analyse the data and interpret the results.
- Whether the request should be referred to a Human Research Ethics Committee.
- If the request is for Aboriginal health information, consideration should be given as to whether the request should be submitted to the Aboriginal Health & Medical Research Council (AH&MRC) Ethics Committee. Disclosure of Aboriginal health information must comply with the AH&MRC if one or more of the following apply:
  - i. The experience of Aboriginal people is an explicit focus of all or part of the research

- ii. Data collection is explicitly directed at Aboriginal peoples
  - iii. Aboriginal peoples, as a group, are to be examined in the results
  - iv. The information has an impact on one or more Aboriginal communities
  - v. Aboriginal health funds are a source of funding
- Consider if the disclosure of unit record data will result in a publication or report, which may have policy implications for the NSW Ministry of Health. If so, the data custodian should discuss the data request with the relevant policy area in the Ministry, and may result in additional conditions placed on the release of the information.

After consideration of the above, if Ethics Committee approval or advice has been obtained where appropriate, and a decision is made to support disclosure of the information, a brief should be prepared containing the following:

- i. A cover brief to:
    - a. The Data Custodian, or all relevant data custodians where data linkage is involved
    - b. Relevant policy area (where appropriate)
    - c. Director, Legal Branch (if legal advice is sought)
    - d. The person legally authorised to approve the data release. Disclosure under the *Health Records and Information Privacy Act 2002* must be approved by the Secretary.
  - ii. An Approval for Disclosure of Information
  - iii. A confidentiality undertaking describing the conditions in the Approval for Disclosure
  - iv. A letter to the data recipient by the person authorised to approve disclosure.
- After the submission is approved and the Approval for Disclosure is signed, the letter and confidentiality undertaking may be sent to the applicant. When the confidentiality undertaking has been signed and returned, the unit record data may be released.
  - Data disclosed must be stored by the recipient in a secure fashion at all times. Data should be strongly encrypted and password protected before being transferred electronically using Accellion Secure File Transfer.

<http://internal.health.nsw.gov.au/ecsd/ssc/howdoi/Acellion-Secure-File-Transfer.pdf>

#### **4.5.2 Process where contractual arrangements exist**

Services managed under contractual arrangements, such as NSW Health funded NGOs may have provisions in place for the sharing of data or information about



the service within the contracts. Such provisions may include authorisation for the NSW Ministry of Health to make information, concerning the service provider, available to other NSW Government Agencies.

Where a detailed process for release of unit record data is not specified within the contract, the above process in Section 4.5.1 may be referred to for guidance.

#### **4.6 Requests for access to data through EDWARD**

EDWARD is NSW Health's Enterprise Data Warehouse for analysis, reporting and decision support.

To be granted access to EDWARD, data users must complete a user access application form and obtain the formal approvals requested.

Approval should first be granted by the staff member's line manager, and Ministry of Health Branch Director.

A considered assessment needs to be made before approving access to both client fully identified or semi-identified data and unrestricted access to sensitive diagnoses and health service data, as many of the sensitive health services have entered into specific client confidentiality agreements which must be honoured.

##### *EDWARD User Access form*

The EDWARD User Application Form is provided below as a PDF that can be completed electronically.

[EDWARD user application form for data analysts and reporting roles \(V11\)](#)

Further guidelines on how to complete the form are provided in the document below.

[EDWARD User Access Guidelines \(Version 1\)](#)

#### **4.7 Requests for data linkage through the Centre for Health Record Linkage**

The Centre for Health Record Linkage (CHeReL) is managed by the NSW Ministry of Health and links multiple sources of data and maintains a record linkage system that protects privacy. Steps involved in accessing NSW data and approaching CHeReL for potential data linkage projects are outlined on their website

<http://www.cherel.org.au/apply-for-linked-data>.

All studies using linked data must have an appropriate legal basis and in most cases require ethical approval.

The CHeReL uses probabilistic linkage procedures, which achieves an estimated false positive rate of 5 per 1000 (0.5%). For each project, the range of linkage errors will be reported to the Chief Investigator.

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## **5 LIST OF ATTACHMENTS**

1. Confidentiality Undertaking for Vendor Staff
2. eHealth Initiative Prioritisation Process Brief

**5.1 Attachment 1: CONFIDENTIALITY UNDERTAKING FOR ACCESS TO [NAME OF DATA WAREHOUSE OR DATA SOURCE]**

I, (full name) \_\_\_\_\_  
(work phone number) \_\_\_\_\_ (work e-mail address) \_\_\_\_\_  
(employed as position title) \_\_\_\_\_  
for and on behalf of (Contractor’s name) \_\_\_\_\_  
and (ACN/ABN) \_\_\_\_\_

agree to abide by the confidentiality and data security conditions and procedures set out in this document.

All public sector agencies in NSW are required to comply with the *Privacy and Personal Information Protection Act 1998* and the *Health Records Information Privacy Act 2002*, which set out rules to protect the privacy of personal information, including health information, in NSW.

By signing this document, I acknowledge in the course of undertaking duties on behalf of the Contractor, that I may have access to personal information, identifying information and health information that relates to individual patients and clients of services associated with NSW Health (**confidential information**). I agree to ensure that confidential information is kept confidential and understand that improper use or disclosure of confidential information may cause harm to NSW Health. I will take proper and adequate precautions at all times to preserve the confidential information.

I will advise the Contractor as soon as I become aware of a possible breach of privacy as a result of my access to the data warehouse and I understand that the Contractor may be required to notify NSW Health of such a breach. I also acknowledge that the confidentiality undertakings given in this document continue even after my engagement with the Contractor ends.

Signed: .....

Date: .....

## 5.2 Attachment 2: eHealth Initiative Brief Template

<b>Initiative Details</b>	
<b>Initiative name</b>	
<b>Date of submission</b>	
<b>Priority</b>	Is this initiative linked to the Premier’s priorities, Ministerial priorities, local executive priorities or other? Please specify.
<b>Funding</b>	Has a source of funding (full or partial) been identified for this initiative?
<b>Estimated Cost</b>	
<b>Contact person name</b>	
<b>Contact person’s organisation/location</b>	
<b>Contact details</b>	Telephone: Email:
<b>Initiative Sponsorship</b>	
<b>Business/clinical sponsor</b>	Who is the Business Sponsor for the initiative (if known) – e.g. Chair of a Clinical Network, Head of impacted department, Director of Workforce etc.
<b>Executive sponsor for the project</b>	Please provide details of the executive sponsor for this initiative, this should be a senior executive within the relevant organisation such as the Chief Executive.
<b>Problem Definition &amp; Strategic Alignment</b>	
<b>Problem Statement and Initiative Overview</b>	Provide a summary of the business problem the initiative is intended to address and the intended business outcomes. Include details of the clinical and/or business drivers, any current system or business processes that will be impacted.

<b>Strategic alignment</b>	Outline how the initiative supports current Health and eHealth strategic plans i.e. eHealth Strategy for NSW 2016-2026.
<b>Stakeholder Engagement</b>	Outline who are the key stakeholders involved in / impacted by this initiative, how they are being consulted and involved in the project, and specify the level of commitment that they have given to the project
<b>Is the project related to an existing initiative</b>	If the proposal relates to an existing system or to a program that is already on the work program, provide an overview of how this proposal relates to the current system and what the dependencies are on the work in progress

<b>Options, Recommended Approach, Costs &amp; Risks</b>	
<b>Options Analysis and recommended approach</b>	What options have been considered to address the business problem and what is the recommended approach?
<b>Impact and Change Management</b>	Who will be impacted by the initiative and how will the change be managed?
<b>Implementation Approach</b>	What would be required to implement the initiative, how would this be managed?
<b>Dependencies</b>	Is the implementation of this initiative dependent on another program of work or other systems, processes being developed.
<b>Project costs</b>	Provide a summary of estimated costs including capital costs and any expected recurrent operating expenditure if known.
<b>Benefits</b>	What key benefits will the initiative deliver e.g. cost savings, time savings, and improved quality of care.
<b>Risks</b>	Outline any key risks to implementing this initiative and how these would be mitigated

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<b>Standards and legislation</b>	Are there any known policy, technical or architectural standards that will need to be applied or any legislative impacts or considerations?
<b>Project governance</b>	How would the project be governed, who would be involved?