Data Collection Policy

1. BACKGROUND
In the course of its operations, WA Health collects, stores, uses and discloses a large volume of data. Data is an important resource used for the clinical care of patients, funding, management, planning, monitoring, improvement, research and evaluation of health and health services in the state.

There are a number of data collections which have been established in WA Health, including some that have been established without consideration or awareness of existing collections containing the same or similar information. The cost involved in the development and ongoing operation of data collections is significant, both financially and in terms of the burden that it imposes on Health Service staff.

Data is a critical resource for the Department and the health system as a whole, and must be managed with regard to the cost of collection, quality of data collected and process undertaken in establishing new collections and justifying the continuation of existing collections.

2. SCOPE
This policy applies to all data collections, including those provided for by statute, held by or within WA Health. It includes collections of patient information, corporate, financial and workforce information where one or more of the following conditions are met:

- The data collection is used to meet business, operational or legislative requirements.
- The State of WA has a strategic need for the information.
- The data collection contains personal information.
- The data collection is used for reporting at a state level, national level, organisation wide or externally.
- The data collection is used across multiple health services.

The scope of this policy includes both paper based (including medical records) and electronic information.

For the purpose of this policy, a data collection includes both operational data collections and data repositories.
3. PURPOSE
The purpose of the Data Collection policy is to support and regulate the establishment of data collections in WA Health by:
- Formalising the establishment of new data collections.
- Ensuring all new data collections are developed with regard to other existing health data collections and strategic initiatives within WA Health.
- Preventing further uncontrolled collection of data.
- Encouraging effective, efficient and accurate collection of data across WA Health.
- Promoting a culture whereby information is seen and managed as a valuable corporate resource.

This policy establishes principles, governance and responsibilities for the establishment and ongoing management of data collections within WA Health.

4. POLICY
The following principles apply to all data collections within scope.

4.1 Fit for Purpose
Information must only be collected when there is a legitimate business purpose which is aligned with WA Health’s strategic intent. Legitimate business purposes for collecting information include, but are not limited to:
- Provision of safe and high quality patient care or treatment.
- Health service administration, evaluation, management and planning.
- Financial and human resource management.
- National Health Reform Agreement reporting.
- Legislative requirements.
- Supporting epidemiology and research.

Data collections must be designed to maximise their usefulness to serve multiple needs, both internal and external to WA Health. The process should not generate a body of data which duplicates information already available within another collection.

4.2 Governance
All data collections within scope must have a Data Steward and Data Custodian(s) assigned. The Data Custodian(s) must be nominated and endorsed by the appropriate Data Steward. Roles and responsibilities for both Data Stewards and Custodians are outlined in the Data Stewardship and Custodianship Policy (OD0321/11).

Approval must be sought for all new data collections. The following outlines the required approval to commence a data collection:
- Enterprise data collections must be approved by the State Health Executive Forum (SHEF) Performance and Reporting Governance Committee (PRGC).
• Local data collections must be approved by the applicable Data Steward of the Health Service and for the Department of Health, the applicable Executive Director.

Staff must not enter data into the collection until the relevant approval has been obtained. The template attached to the Data Stewardship and Custodianship Policy must be completed documenting the details of the collection, including:

- A clear purpose for the collection, justifying the basis for the collection, including confirmation that the information is not already collected within WA Health.
- Impact and benefits of the new collection on WA Health, including staffing, training requirements, improvement in patient safety and quality, etc.
- Costs of setting up and maintaining the collection.
- Data Custodian(s) nominated and endorsed by the appropriate Data Steward.

Major modifications to existing data collections must be endorsed by the Data Steward. Major modifications are defined as:

- The inclusion of additional data elements that will change the scope, context or purpose of the collection.
- Any change to the data collection that will result in changes to work processes or practices.
- Any change to the data collection that is sensitive or political in nature.

Documentation to the Data Steward detailing the reasons for the modifications must include:

- Details of the change required.
- Breakdown of the costs in terms of information technology hardware, software and human resources.
- Time involved in developing and implementing the modifications, including any down-time.
- Impacts on service provision, patient care and reporting obligations.
- The benefits expected from the modification.

4.3 Efficient and Effective

The importance and benefits of the data collection must be weighed up with the cost of the collection. Cost relates to the resources used in supplying, collecting, processing, storing and using the information within the collection. The selection of a suitable data collection system must reflect the choice of the least costly option to fit the decision making needs of WA Health.

The data collection must also be designed to maximise its usefulness by ensuring information is collected once (to reduce duplication) and used multiple times.
4.4 Transparent and Interpretable
Data within the data collection must be clearly documented to ensure the information is relevant for the required use. This also ensures the information from the collection is transparent and interpretable.

A data dictionary must be developed to describe the contents, format and structure of the collection and the relationships between its elements.

4.5 Accuracy
Accuracy of the data leads to greater efficiencies within WA Health. To ensure a high level of data accuracy:

- Information should be collected as close to the source as possible to ensure accuracy.
- Information must be entered correctly at point of collection.
- Guidelines and business rules on data collection must be made available to staff entering data.
- System checks such as data format checking, edit validations and mandatory checks must be put in place to prevent invalid data from being entered.
- Audit checks must be conducted on a regular basis.

4.6 Classification
Information collected should be classified in terms of its sensitivity and criticality to WA Health. The classification assigned places controls relating to the type of information collected and its need to remain confidential and secure. For further information refer to OD0304/10 Information Classification Policy.

4.7 Ethics, Privacy and Security
Information within the collection must be a fair representation of the facts, equitable and of high accuracy, whilst maintaining privacy and security of individuals and other sensitive information.

Information must be collected in an ethical manner, taking into consideration the rights and privacy of individuals. Data Custodians must only collect as much personal information as the collection requires in order to fulfil the purpose of the collection. Staff are required to conform to acceptable standards of professional behaviour when collecting information.

The Data Steward is responsible for:

- Overseeing the development of a role based Information Access Control model that specifies the types of users who can access the data collection and the level of access permitted. This model may be developed by the Data Custodian with endorsement by the Data Steward. For further information refer to OD0360/12 Information Access and Disclosure Policy.
• Overseeing the development of an Information Disclosure model which specifies the level of approval required prior to releasing information from the data collection based on the granularity and sensitivity of the information requested. This model may be developed by the Data Custodian with endorsement by the Data Steward. For further information refer to OD0360/12 Information Access and Disclosure Policy.

Data Custodians are responsible for:
• Implementing the Information Access Control model and Information Disclosure model.
• Preserving and protecting the integrity of information within the collection by ensuring that the data is stored in a secure environment.
• Ensuring the recipient of the data fully understands the conditions of data release and their related obligations.

When third parties are collecting data on WA Health’s behalf a contract between WA Health and the third party must be developed. Types of contracts include Memorandums of Understanding (MOU) and Service Agreements. These contracts ensure the confidentiality and security of the data.

The following elements must be outlined within the contract to ensure:
• ownership of data;
• storage and security of data;
• retention of data - in accordance with the WA Health record keeping plan and State Legislation;
• WA Health’s audit requirements; and
• disposal of data after the contract expires.

4.8 National Aboriginal and Torres Strait Islander Health Data Principles
In October 2006, the Australian Health Ministers’ Advisory Council (AHMAC) endorsed the ‘National Aboriginal and Torres Strait Islander Health Data Principles’. These 11 principles set out a culturally respectful foundation for the collection, storage and use of Aboriginal health and health related information.

The National Aboriginal and Torres Strait Islander Health Data Principles should be applied, where applicable when creating, reviewing or modifying a data collection.

4.7 Management of Personal Information – Good Practice and Opportunities for Improvement – Western Australian Ombudsman
On 28th March 2011, the Ombudsman published a report, “The management of personal information – good practice and opportunities for improvement”, following an investigation of selected State Government agencies that deal with large amounts of personal information.
Good practice principles were developed to assist Government Agencies in managing personal information they collect and hold. These principles are based on national and state legislative requirements, agency-specific legislation and internationally accepted good practice.

These principles should be reviewed and applied (if applicable), in conjunction with all WA Health Information Management policies.

5. DEFINITIONS

A Data Collection is a systematic gathering of data for a particular purpose from various sources, including manual entry into an information system, questionnaires, interviews, observation, existing records and electronic devices. This includes both operational data collections and data repositories.

Data Custodian – The person(s) responsible for the day-to-day management of data from a business perspective. The Data Custodian aims to improve the accuracy, usability and accessibility of data within the data collection.

Data Dictionary – A centralised repository of information describing the contents, format and structure of a database and the relationships between its elements.

Data Repository – Data that is collected from various sources, including operational data collections for the primary purpose of monitoring, evaluation, reporting and research. Examples of data repositories include data held within the Hospital Morbidity Data Collection, Finance Data Warehouse and the Emergency Department Data Collection (EDDC).

Data Steward – A delegated person responsible for setting the overall strategic direction of a specific data collection. They ensure the collection is developed, maintained and utilised in accordance with the strategic goals of WA Health. Data Stewards are also responsible for authorising access, use and disclosure of data from the data collection for clearly defined purposes that comply with WA Health’s statutory obligations.

Operational Data Collection – A collection of data as part of the day-to-day activities of an area for the primary purpose of tracking and managing the operational aspects of the area. The operational data collection is typically a transaction-based system which contains detailed data elements to represent the activities of the area. Examples of operational data collections include data held within Patient Administration Systems, TRIM, Financial Systems and Human Resource Management Systems.

Personal Health Information pertains to all health information where the identity of a person is apparent or can reasonably be ascertained from the information itself. Information is also personal information if it is reasonably possible for the person receiving the information to identify the individual by using other information that they already hold.
6. ASSOCIATED POLICIES, STANDARDS, GUIDELINES and DOCUMENTS

Data Stewardship and Custodianship Policy OD 0321/11
Information Classification Policy OD 0304/10
Information Access and Disclosure Policy OD0360/12

7. RELEVANT LEGISLATION

Health Act 1911
Health Services (conciliation and review) Act 1995
Hospital and Health Services Act 1927
Human Reproductive Technology Act 1991
Mental Health Act 1996 (WA)
Freedom of Information Act 1992
Financial Management Act 2006
Public Sector Management Act 1994
State Records Act 2000

8. SUPPORTING DOCUMENTS

Department of Communities, Queensland Government, Principles for Data and Information Collection, Storage, Sharing and Use

Australian Institute of Health and Welfare (AIHW), Quality and availability of Indigenous statistics, National Aboriginal and Torres Strait Islander Health Data Principles

Management of Personal Information – Good Practice and Opportunities for Improvement – Western Australian Ombudsman