

Information about your Health Data



Delivering a Healthy WA

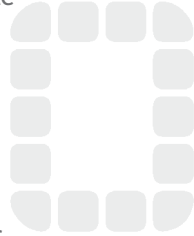
Contents

1. Introduction	2
2. Common Questions	3
Q1. What are statewide health data collections?	3
Q2. Does the Department collect information from my GP?	3
Q3. Is my consent required for my health information to be collected?	4
Q4. Can I opt out of the collection of my health information?	4
Q5. How does the Department use health information?	4
Q6. Is the information used for research?	4
Q7. Is the information stored securely?	5
Q8. Is there any independent external auditing of the security of the statewide data collections?	5
Q9. How is my privacy protected?	5
Q10. What is the Confidentiality of Health Information Committee?	6
Q11. Does the Department of Health keep all my personal health information in a single database?	6
Q12. What is 'data linkage'?	7
Q13. Are there risks that non-identifiable information can be re-identified?	7
Q14. What are the governance arrangements around the health data collections?	8
Q15. Does the Department of Health share my personal health information with other government agencies?	8
Q16. Am I able to access my health information held by the Department of Health?	8
Q17. What if I have a comment or complaint directed to the Department of Health regarding the statewide health data collections?	9
3. Further Information	10
About statewide health data collections	10
About The Use Of Information	13
4. Health Data Collections	16
A List of Data Collections in WA Department of Health	16
Examples of collections linked with WA Department of Health data	17
5. Glossary	18

1. Introduction

This booklet tells you about health information collected by the Department of Health. The Department is responsible for data collections that capture information about the contact Western Australians have with the health system. Such information has been collected for many years and is used to plan for future health services, to report to both the WA State and the Australian Government and to conduct research that results in better health services.

To make it easy for you to find out what you want to know the second section of this booklet deals with common questions about this health information. The third section provides more detail about the data collections and the use of the health information. A glossary of terms is also provided.



2. Common Questions

Q1. What are statewide health data collections?

A statewide health data collection is a database held by the Department of Health. It is made up of summaries of patient information collected from all relevant health service providers (for example, hospitals, pathologists, midwives) in the State.

Whenever you receive care from a health service provider, such as a hospital or a midwife, some information about you and your health care is sent to the Department of Health. The data the Department receives is only a coded summary of the health care you received on that occasion. It is not the same as the health record used for your clinical care.

Some examples of statewide health data collections are:

- Hospital Morbidity Data Collection, containing data about every patient admitted to WA hospitals
- Non-Admitted Patient Data Collections, several databases of information about emergency department, outpatient clinic and community health visits at public health services
- Mental Health Information System, containing data about the use of public mental health services in WA
- WA Cancer Registry, containing data about all reported instances of cancer
- Maternal and Child Health Registry, containing data on birth events, birth outcomes and associated childbearing matters
- WA Notifiable Infectious Diseases, databases containing information about reported instances of the 62 notifiable infectious diseases.

Q2. Does the Department collect information from my GP?

Most of the information is collected from hospitals, pathologists and midwives, not GPs. Only a small amount of information is collected from GPs, for example, for notifications of infectious diseases.

Q3. Is my consent required for my health information to be collected?

Your consent is not required. The Department is authorised by legislation to collect your health information.

Q4. Can I opt out of the collection of my health information?

No. Your health service provider has a legal obligation to send information about your health care to the Department because all Western Australians benefit from reliable information about health.

Q5. How does the Department use health information?

The information collected by the Department is not used for your clinical care. It is used by Department of Health staff for health service planning and performance monitoring. Some information is also reported to the Australian Government for funding purposes. You have no choice about the use of this information because it is used for managing the health system.

Q6. Is the information used for research?

Qualified researchers external to the Department may be granted access to some information for projects that can benefit the community. Applications for information by researchers are only considered after review and approval of relevant ethics committees. Most information provided to researchers is non-identifiable. Where identified information is necessary for a research project then the researcher must meet more requirements.

Most research is only allowed if people give their consent to their information being used. However, when we need to know about the whole population it is not practical to ask consent from everyone.

Further information about the use of information by researchers is given in the section of the booklet *About the use of information*.

Q7. Is the information stored securely?

As with any collection of information stored electronically there are risks of unauthorised access. The Department of Health uses best practice (that is, measures are in place that experts consider the best way to secure information on computers) to maintain security. Personal health information is held only in secure settings, where both physical and systems security measures are in place.

Q8. Is there any independent external auditing of the security of the statewide data collections?

The Auditor General conducts audits on all functions of the Department of Health. The Auditor General is a key provider of independent and impartial information on public sector accountability and performance to the Parliament. The Office of the Auditor General has a responsibility to the community as its 'watchdog'.

Q9. How is my privacy protected?

To protect against the risk of unauthorised disclosure, everyone who has access to your personal health information for their work is bound by legal duties to keep the information confidential. They must keep the information secure and protect it from misuse. All Department of Health staff with access to personal health information must sign a Confidentiality Agreement. If any staff member disclosed information without proper authority they would commit a criminal offence.

Researchers who are authorised to receive personal health information must also sign a Confidentiality Agreement that includes legal obligations to keep the information confidential.

To protect against the risk of individuals being recognised, wherever possible non-identifiable information is used for analysis and research. This means that all the information that could be used to identify a person is removed from the information about that person's health. All projects are checked to make sure that no unnecessary information is provided.

Government reports produced using the information do not contain any information that could identify individuals. Research reports must not identify an individual unless the person has given consent. This ensures that information can be used for community benefit while privacy is protected.

Sometimes analysts and researchers cannot complete project work without identifiable information. If individuals agree to their information being used then the Department of Health can provide the information for the agreed purpose. However, sometimes it is impossible to ask people for their consent because it may not be possible to contact them. Sometimes the project may need the identified information from hundreds of thousands of people or even from everyone in WA. The results of the analysis would not be correct unless everyone is included. In these circumstances the Confidentiality of Health Information Committee will decide whether the public interest in the project is more important than the public interest in the protection of privacy. The Confidentiality of Health Information Committee will also decide whether the privacy and security of the information is properly protected.

Q10. What is the Confidentiality of Health Information Committee?

The Confidentiality of Health Information Committee is an independent committee comprised of community members, people who provide health care, lawyers and researchers. Some members have special skills in research, health, ethics or information security and others represent the community. The committee considers if a research project meets the ethical standards set by the National Health and Medical Research Council. The Department of Health will only release personal health information from a data collection if the Confidentiality of Health Information Committee approves the project.

Q11. Does the Department of Health keep all my personal health information in a single database?

No. Health information is held in a number of databases that are both physically and logically separate.

Q12. What is ‘data linkage’?

Data linkage is a process of keeping track of the separate bits of information about one person in each separate data source. This is done by assigning an identifying number to each person and storing a set of links to all records for the person. The information about the person is not brought together in one place. It stays in the separate data collections and the security and means of access to the information in each source remain unchanged.

When the information about a person is ‘linked’ together in this way, users can tell, without knowing the identity of the person, the difference between something happening twice to one person or once to two people. This is very important when planning for future health care needs or studying the health of our population.

Links have been made in this way between the different databases in the Department of Health and also to data sources in other WA State departments and Australian Government data sources such as the Pharmaceutical Benefits Scheme and Medical Benefits Scheme data. This means that information can be obtained from these sources without having to reveal the identity of individuals. The Family Connections Project has also linked the health history profiles of related individuals.

The Data Linkage Unit in the Department of Health is responsible for creating and maintaining the links between the main statewide health data collections and other approved data sources. The establishment of linkages between new data sources must be approved by the Confidentiality of Health Information Committee.

Q13. Are there risks that non-identifiable information can be re-identified?

When analysis with large data sets occurs, there is the risk that de-identified individuals are ‘re-identified.’ This risk is extremely low, but may occur when people have very rare conditions or when data from two data sets is linked. However, analysts and researchers are legally and ethically obliged to protect the privacy of individuals inadvertently re-identified by analysis or by the data linkage process.

Q14. What are the governance arrangements around the health data collections?

The data collections are managed by the Western Australian Department of Health, a State Government agency. The Department is bound by the *Public Sector Management Act* and all staff in the Department are bound by the Public Sector Code of Conduct.

Senior managers in the Department are responsible for the statewide data collections. It is their responsibility to ensure the safety and security of data in the statewide collections and permit access to the data only under certain controlled conditions.

Q15. Does the Department of Health share my personal health information with other government agencies?

The Department is required to report health system activity to both the Australian and WA Governments. The Australian Department of Health and Ageing requires the information at patient level. This means that it is identifiable. Staff in other government departments do not have access to the Department of Health information collections. Requests for information from other government departments must pass the same approvals process as any other information request.

Q16. Am I able to access my health information held by the Department of Health?

You are able to obtain copies of your own information through the *Freedom of Information Act 1992*. The summary information held in the Department of Health is rarely useful for providing individual health care. Further information about Freedom of Information can be obtained from the Office of the Information Commissioner on 9220 7888.

Q17. What if I have a comment or complaint directed to the Department of Health regarding the statewide health data collections?

Comments or complaints specifically about the collection, use or disclosure of health information by the Department of Health can be made by writing to the Department of Health. Correspondence should be addressed to:

Information Planning Unit
Information Collection and Management
WA Department of Health
PO Box 8172
Perth Business Centre
Perth WA 6849

Telephone (08) 9222 4222
Facsimile: (08) 9222 4236

3. Further Information

About statewide health data collections

The Department keeps health information about different things in separate data collections. This section describes some of the core data collections. There is a complete list of the Department's statewide data collections in the fourth section of this booklet.

The Hospital Morbidity Data Collection

The Hospital Morbidity Data Collection is a database of information about hospital visits. The collection began in 1970 and includes summaries of all hospital visits for patients admitted to public and private hospitals in Western Australia. It is an important information resource used by the Department of Health, contributing hospitals and researchers. It is the largest of the Department's statewide health data collections. The data collection is comprised of:

- summary inpatient records since 1970, which is the data about patient visits to hospitals
- wait list data since 1991 - data about people waiting for elective surgery.

The collection of morbidity information is authorised under law by the *Hospitals and Health Services Act 1927*.

Non-admitted patient data collection

Non-admitted patient data collections are authorised under law by the *Hospitals and Health Services Act 1927*.

- The Emergency Department Data Collection is a collection of information about all patients who attend emergency departments at public hospitals in WA. Emergency services in rural health settings are also collected. Additionally, some private hospital data is collected. This information has been collected since July 2002.
- The Outpatient Data Collection contains information about all visits by patients at outpatient departments (including such things as physiotherapy, occupational therapy and speech therapy) at WA public hospitals.

Additionally, community health information is collected each time a service is provided to a person or group of people by publicly funded Child and Community Health Centres in WA. Information is about the services provided by each centre.

Mental Health Data Collection

The Mental Health Information System collects data about people who use public mental health services in WA. It is a patient based information system in which each patient is allocated a unique number. Data for each person contains demographic information and clinical information from outpatient clinics and hospital visits.

The collection of mental health information is authorised by *Hospitals and Health Services Act 1927* and has been collected since 1966.

The Western Australian Cancer Registry

The WA Cancer Registry is a database of all the instances of cancer in WA, which are reported by all oncologists and pathologists to the Department of Health. In addition to clinical data, the database includes the names, addresses and demographic information of patients diagnosed with cancer. The Registry was established by the *Health (Notification of Cancer) Regulations 1981*. The Registry produces an annual statistical report on cancer incidence, cancer-related death and a variety of special topics.

The Maternal and Child Health Registry

The Maternal and Child Health Registry provides the Department of Health with comprehensive Statewide data on birth events, birth outcomes and associated childbearing matters in accord with the requirements of the *Western Australian Health Act 1911*.

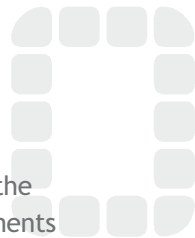
Under the *Health (Notifications by Midwives) Regulations 1994*, midwives are required to provide the Department of Health with information about each birth they attend, either at a hospital or home setting in WA. In addition to clinical information about the birth, the data provided includes the mother's name, address and demographic information.

The Reproductive Technology Register

The Reproductive Technology Register is an identified data collection of all in vitro fertilisation and donor insemination treatments conducted in WA. It is required by the *Human Reproductive Technology Act 1991*. All patients are advised of their inclusion on the register before treatment. This register provides public health information on in vitro fertilisation and associated procedures. Information from this source is published annually in the Reproductive Technology Council Annual Report.

The Birth Defects Register

Information about babies born with birth defects in WA since 1980 is recorded in the Birth Defects Register. This includes information from the Maternal and Child Health Registry that is collected under the requirements of the *Health (Notifications by Midwives) Regulations 1994* and information from the Hospital Morbidity Data Collection collected under the *Hospital and Health Service Act 1927* and other clinical information. The Birth Defects Register is maintained at King Edward Memorial Hospital.



About The Use Of Information

Health system management

Most health service managers use data collected and held by the health service at which they work. However, some planning needs to look at the health system as a whole or let one health service compare its operation with that of another similar organisation. This exchange of information allows the health system to identify the best way of working and from this information improve other health services.

Information about health system activity that is provided to managers and analysts working for those managers is non-identifiable so that individual patients and health professionals are unknown. When data about another health service is accessed the identity of the organisation may also be kept confidential.

Managers across the health system use this non-identifiable or statistical data in decision-making. It assists them to:

- identify areas in need of improvement
- identify where the system is working well so the example can be followed
- plan things such as nursing staff allocations in public hospitals or where vital equipment such as dialysis services should be provided.

Although most of these reports are internal, the Department of Health's Annual Report provides the public with similar information on the performance of the health system.

Australian Government reporting

Under the Australian Health Care Agreement and the National Health Information Agreement all states and territories of Australia must provide information to Commonwealth agencies such as the Department of Health and Ageing, the Australian Institute of Health and Welfare and the Department of Veterans' Affairs. This information is required to compile national health statistics and so that WA and the other states and territories receive funding to provide essential health care to our communities.

All states and territories of Australia are represented on the Health Data Standards Committee. After agreement by Health Ministers and the heads of Health Departments, the committee devises National Minimum Data Sets to meet the information requirements of the agreement. The committee also determines common definitions so that data from different sources has the same meaning and can be compared. The purpose of this data is twofold. Firstly, it allows the federal government to monitor how health dollars are spent, and secondly, it provides statistical information to monitor health practice and population health.

Research

Access to health information is granted to qualified researchers who meet strict requirements. Research is conducted by qualified staff, such as medical doctors, who study the factors affecting health and illness in populations. These researchers work in the WA Department of Health, in WA hospitals, health services and universities as well as in research institutes such as the Telethon Institute for Child Health Research. Sometimes the research is conducted by similar researchers in other states, and occasionally WA researchers work with researchers overseas.

We can identify the connection between risk factors or positive behaviours and their effect on people's health by conducting research. Some time ago, health researchers identified the connection between smoking and lung cancer that we now all know about. More recently, health researchers discovered the health benefits of getting as little as 30 minutes of mild exercise a day. The Department of Health ran a campaign to inform people to "Find 30" minutes to do some exercise.

All research projects must have been granted ethics approval by an institutional Human Research Ethics Committee and must satisfy the principles in the National Health and Medical Research Council National Statement on Ethical Conduct in Research Involving Humans.

The data required by researchers will vary depending on the type of research being conducted. Some studies may be looking at a very localised group, such as people living near an industrial area, and others may compare data from everywhere in Australia. Researchers requiring Australia wide information would usually approach the Australian Institute of Health and Welfare to obtain the data.

Most research is done using information that does not have any names and addresses or anything that can identify people. Sometimes identifiable information is needed. In these cases the Confidentiality of Health Information Committee (CHIC) must approve the research as well as the institutional Human Research Ethics Committee. These committees are made up of community members, people who provide care in the community, lawyers and researchers.

Usually research is only allowed when people give their consent. However, sometimes it is not practical to contact every person for their consent, for example, if the research involves everyone in WA over a long period of time. In circumstances like these, the CHIC will decide whether it is in the public interest for the research to be done and you will not have any choice about the use of your information.

If researchers want to collect more information from you the Department will contact you to ask if you want to participate in the research. In this case, you decide whether to participate or not. If you agree, the researcher will then contact you. If you do not agree you will not be involved. Your health care will not be affected if you choose not to be involved.

Researchers must follow the requirements which impose strict obligations to ensure the security and confidentiality of the information. In addition, data custodians may place further restrictions on the release of the data.

Researchers are required to maintain the confidentiality of information and research reports published do not identify individuals unless the person has given written consent.

4. Health Data Collections

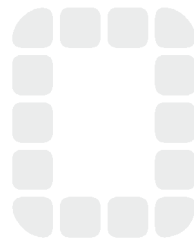
A List of Data Collections in WA Department of Health

Information Collection and Management

Anaesthetic Mortality Information Collection
Community Health Data Collection
Elective Surgery Waiting Lists Data Collection
Emergency Department Data Collection
Hospital Morbidity Data Collection
Maternal Mortality Information Collection
Mental Health Information Collection
Midwives' Notification System
Outpatients Data Collection
Perinatal and Infant Mortality Database
Reproductive Technology Register
Voluntary Donor Register
WA Cancer Registry
WA Mesothelioma Register

Health Protection Group

Breast Cancer Screening Registry
Cervical Cytology Registry
Hepatitis B & C Register
Immunisation Register
Leprosy
Notifiable Infectious Diseases Database (WANIDD)
Notification of Adverse Events after Immunisation
Notification of HIV Infection Database
Notification of Venereal Diseases
Mycobacteria Reference Laboratory Statistics



TB Register
Trachoma
Monitoring of Drugs of Dependence System (MODDS)
Notification of Lead Poisoning

Analysis and Performance Reporting

Patient Electronic Referral Liaison System
WA Consumer Evaluation of Health Services
WA Health and Well-being Surveillance System

Health Policy and Clinical Reform

Aged Care Assessment Team Data Collection
Home and Community Care Data Collection

Examples of collections linked with WA Department of Health data

WA Maternal and Child Health Research Data Base (Telethon Institute of Children Health Research)
WA Cerebral Palsy Register (TICHR)
WA Twins Register Data Collection (TICHR)
Intellectual Disability Exploring Answers (TICHR)
WA Register for Autism Spectrum Disorders (linked 1999-2002) (TICHR)
Residential aged care data (Department of Health and Ageing)
Medicare Benefits Schedule (Department of Health and Ageing)
Pharmaceutical Benefits Scheme (Department of Health and Ageing)
Busselton Health Surveys (Busselton Population Medical Research Foundation)
Birth Defects Register (King Edward Memorial Hospital)
Alcohol and Drug Authority Data Collection (Alcohol and Drug Authority)
Silver Chain Nursing Data Collection (Silver Chain Nursing Association)
St John's Ambulance Services Data Collection (St John's Ambulance Services)

5. GLOSSARY

Community health

Community health services are services provided in community settings that do not require hospital infrastructure. Services include health promotion and education, family care (including screening, immunisation and treatment of infants and school aged children), health care to those who may have special needs (such as Aboriginal people, women, people with severe disability or disease, older people and people in remote areas), nursing and therapy services, palliative care and multicultural services.

Data custodian

A data custodian is the person who is responsible for managing a data collection or database. The term custodian is used to make it clear that this person does not own the data they only manage it.

Demographic information

Demographic information refers to data about personal characteristics that can be grouped such as age, gender, location of residence or nationality. This information is vital for statistical research as it enables population groups to be identified rather than individuals.

Diagnosis

A diagnosis is the health condition that a health care provider determined is the reason why a patient requires care, such as a specific type of infection, disease or an injury.

Health Record

A Health Record, sometimes called a Medical Record or Patient Record, is the details of a person's health care. It includes key information about each health event including diagnoses, test results, procedures and treatments, but it also has details such as doctor's notes, medications prescribed, measures taken (e.g, heart rate or blood pressure). Today a portion of your health record is stored manually, as a paper record, and other parts are stored electronically on a computer. The Australian health care system is currently working towards complete Electronic Health Records for all Australians.

Identified data

Identified data is data that contains information that could be used to identify a person. This could be a number that has been assigned to the person, like a Medicare number or driver's licence number. In the public health system in WA each patient is assigned a Unique Medical Record Number (UMRN). Identified data may also be data that includes the person's name, date of birth and address.

Inpatient

An inpatient is a patient who has been admitted to a hospital.

Morbidity

Morbidity refers to the relative incidence of disease. It is not about deaths, which is mortality. Morbidity data is data about diseases and other health conditions such as injuries, which is used to determine how often diseases occur in the population.

Non-identifiable data

When health data is non-identifiable it means that all the data that could be used to identify a person is removed or separated from the data about that person's health. That includes any numbers that are identifiers, like a Medicare number and the name, date of birth and address. Sometimes de-identification needs to remove even more data, for example where there is only one or two people of a particular ethnic group in a community any information about ethnicity and/or any information that identifies the community would need to be removed for de-identification to be effective.

Outpatient

An outpatient is a patient who attends an outpatient clinic at a hospital, which provides health care that does not require a stay in hospital or use of a hospital bed.

Personal health information

If it is possible to identify a particular person from the information about their care then the information is called personal health information.

Record

In computer terms a record is a row of related data stored in a database. It is very similar to a row of figures in a spreadsheet.

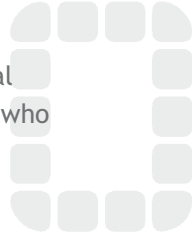
In the health system a record could contain such data as a record number, name, date of birth, date of hospital visit, length of time in hospital, diagnosis or procedure.

Statistics

Statistics refers to a collection of quantitative data that is a numerical representation, such as the number of people in different age groups who had falls from injuries resulting in a hospital visit.

Treatment

Treatment is the actions taken by a health care provider intended to improve a patient's health.





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