



Centre of
Research Excellence
in Patient Safety

NHMRC Centre of Research Excellence in Patient Safety

Register of Registries report

Foreword

This document was developed to highlight registries currently in existence in Australia and capable of measuring quality of care at either an institutional or clinician-specific level.

To be eligible for inclusion in this registry, the proposed registry must:

- (1) collect patient or clinician-specific data continuously;
- (2) collect outcome data as a function within the registry, and not primarily through linkage with outcome databases such as the Registry of Births, Deaths and Marriages or the National Death Index;
- (3) collect information pertaining to more than one healthcare institution.

It should be noted that there are a number of population-based registries which we have not included because they contain limited clinical information and, in themselves do not contain sufficient information to enable risk adjustment to be undertaken. Many of these are based in the Australian Institute for Health and Welfare (AIHW) and include:

- National Diabetes Registry
- Australasian Association of Cancer Registries
- Registry of Births, Deaths and Marriages
- National Hospital Morbidity Database
- National Community Mental Health Care Database

There are many important data sources to be considered when evaluating quality of care issues, both within the acute public health sector and in the wider community. The Pharmaceutical Benefits Scheme (PBS) database, which captures details of medicines subsidised by Medicare Australia is one such noteworthy data source. Medication use may be used as a proxy for disease burden. Details of this registry are not contained in this document

General Practice currently has limited ability to monitor quality of care. The Bettering the Evaluation and Care of Health (BEACH) study, commenced in 1998, collects patient specific data, outcome data and information pertaining to the GP encounter however was not included in this registry because it did not continuously collect data. Collection of data is restricted to collecting details of 100 encounters for 1000 GPs.

Search Strategy:

Registries were identified using the following strategies:

- peer consultation,
- Medline search using MeSH subject heading, "REGISTRIES, AUSTRALIA" and keyword terms, "REGISTRY, DATABASE, AUSTRALIA, REGISTER"
- Web-based search using Google search engine

We identified thirty five registries meeting the inclusion criteria (Table 1).

Table 1: Registries in existence in Australia

Registry monitors management of:	Registry name	Total no. of registries
Trauma*	CONROD trauma registry (Qld) VSTORM (Vic) South Australian Trauma registry (SA) Victorian Orthopaedic Trauma registry (Vic) Trauma Registry, Royal Perth Hospital (WA)	5
Intensive Care	ANZICS registry (Aust)	1
Vascular surgery	Melbourne Vascular Surgical Audit Program (Vic)	1
Cardiac surgery/cardiology	Australian Society of Cardiothoracic Surgeons Database Project (Aust) Melbourne Interventional Group Interventional Cardiology Registry (Vic)	2
Rheumatology	Aust Rheumatology Association Database (Aust)	1
Cardiac Arrest	Western Australian Pre-Hospital Care Database (WA) Victorian Cardiac Arrest Registry (Vic)	2
Bleeding disorders	Haemostasis registry (Aust) Australian Bleeding Disorder Registry (Aust)	2
Infection Control	South Australian Infection Control Surveillance database (SA) Centre for Healthcare Related Infection Surveillance and Prevention (Qld) Victorian Infection Control (Vic) Nosocomial Infection Surveillance System (Vic)	3
Clinical cancer	South Australian Clinical Cancer Registry (SA) ACCORD Patient Database (Vic) NSW Concord Colorectal Cancer Registry (NSW) NSW Clinical Cancer registry (NSW)	4
Screening	National Bowel Screening Registry (Aust) Cervical Cytology Registry (Aust) BreastScreen Australia (Aust)	3

Registry monitors management of:	Registry name	Total no. of registries
Transplantation	Australian and New Zealand Liver Transplantation Registry (Aust) Australian and New Zealand Cardiothoracic Organ Transplantation Registry (Aust) Australian and New Zealand Dialysis and Transplantation Registry (Aust) Australian Corneal Graft Registry (Aust) Australian Bone Marrow Transplantation Registry (Aust)	5
Joint Replacement	Australian Orthopaedic Association Joint Replacement Registry (Aust)	1
Specific diseases	Australian Motor Neuron Disease Registry (Aust) Australian Cystic Fibrosis data registry (Aust) National Creutzfeldt Jacob Disease (Aust) Australian Motor Neuron Disease registry (Aust)	4

* Fremantle Hospital also has a trauma registry but details not available at time of publication. A national trauma registry consortium exists and is based in the University of Queensland (<http://www.uq.edu.au/ntrc/>)

Many hospitals have developed “in house” registers for diseases and surgical procedures. Hospitals develop these registries principally to assist in the audit process. Some of these registers are growing in size and exist within healthcare networks rather than individual hospitals.

Future work is required to determine whether these databases can be merged to create a larger registry. Of concern will be whether data definition are consistent between registries and whether risk adjustment can be adequately performed to enable robust analysis of findings.

While we undertook an extensive search to identify registries, there may be registries in existence which will not be identified using this technique. To be more confident that all pertinent registries have been captured, craft groups/ professional organisations should be contacted. This will include the Royal Australasian College of Surgeons (RACS), Royal Australian College of Physicians (RACP), Royal Australian College of General Practitioners (RACGP) Australian and New Zealand College of Psychiatry. This was not within the scope of this project.

Attached as Appendices to this document are the database questionnaire (Appendix A) and letters to database custodians (Appendix B).

Summary report of registries

REGISTRY NAME	NSW Concord Colorectal Cancer Clinical Registry
Type of Registry	Care Management
What is the common circumstance that determines inclusion in the registry?	Resection for adenocarcinoma or colon and rectum.
What is the primary outcome collected by the registry?	Death, recurrence
Is there any bias associated with the outcome due to the way in which it was reported?	Independent observer not blinded to the intervention
What geographical area is covered by the registry?	South West Sydney Health Service- referral hospital for wider geographical area
Which group, if any, is not represented in the registry yet ought to be?	Larger population group
Have subjects given consent for data collection?	Subjects informed individually of data collection and use to which it will be put
What is the level to which subjects have consented?	Opt in- Signed consent obtained only on first contact with the service
Date in which data was first collected	1/01/1971
Number of individuals/ episodes of care included in the registry	4000
Date in which this was determined	1/04/2007
How is data collected?	Paper-based reporting
If the registry documents management of patients, for what period of time are individuals followed up?	15 years /death
If nationally approved codes are used to identify the subject, clinician or institution, what is link key?	Medical record number / hospital name
To which other database is linkage routinely undertaken?	Administrative database within hospital
How are records stored on the database?	Identifiable
Is the registry endorsed by any clinical/professional association?	No
Was a Steering Committee established when the registry was developed?	No
Is a Management Committee supporting the registry?	Yes
How often does the Management Committee meet?	Weekly
Have Terms of Reference been established with reporting processes to address issues?	No
What is the source of funding for the registry?	No explicit funds
What proportion of the eligible population is included in the database- how complete is the dataset?	Most (90-97%)
How and when was completeness of the registry last determined?	ICD codes, pathology results, discussion with staff
What variables are included in the registry?	Identifier_condition_ intervention_ short term outcome_major known confounders_long term outcome

Summary report of registries

REGISTRY NAME	Queensland Trauma Registry- CONROD
Type of Registry	Care Management
What is the common circumstance that determines inclusion in the registry?	Trauma cases meeting the following criteria; (1) > 14 years admitted to a registry hospital site for > 24hrs on initial presentation for treatment of an injury and are codeable to an ICD-10 category from S00-S99, T00-T35, T63, T66-T71, T75; (2) <14 years and admitted to a registry hospital site for > 24hrs on initial presentation for treatment of an injury and are codeable to an ICD-10 category from S00-S99, T00-T75, T78 (Appendix 7); (3) Patients who die during ED presentation after active treatment in the ED; (4) Patient who die during hospital admission
What is the primary outcome collected by the registry?	Monitoring trauma management throughout Queensland
Is there any bias associated with the outcome due to the way in which it was reported?	Observer neither independent nor blinded to the intervention
What geographical area is covered by the registry?	Queensland: Cairns, Townsville, Mackay, Rockhampton, Nambour, Redcliffe/Caboolture, RCH, Mater Childrens Hosp, Royal Brisbane and Womens' Hospital, Princess Alexandra, Toowoomba, Ipswich, Gold Coast
Which group, if any, is not represented in the registry yet ought to be?	Only public hospitals are included
Have subjects given consent for data collection?	Subjects informed collectively of data collection and use to which it will be put
What is the level to which subjects have consented?	Opt off- Signed consent not obtained but option to be removed from registry
Date in which data was first collected	1/01/1998
Number of individuals/ episodes of care included in the registry	54144 individuals
Date in which this was determined	11/09/2006
How is data collected?	Paper-based reporting
If the registry documents management of patients, for what period of time are individuals followed up?	Until discharge
If nationally approved codes are used to identify the subject, clinician or institution, what is link key?	Patient identifiers, hospital identifier
To which other database is linkage routinely undertaken	Emergency Department Information System (EDIS), Hospital Based Corporate Information System (HBCIS)
How are records stored on the database?	Identifiable
Is the registry endorsed by any clinical/professional association?	Yes, The Royal Australasian College of Surgeons
Was a Steering Committee established when the registry was developed?	No
Is a Management Committee supporting the registry	Yes
How often does the Management Committee meet?	Monthly
Have Terms of Reference been established with reporting processes to address issues	Yes
What is the source of funding for the registry?	Public sector(DHS/Uni)
What proportion of the eligible population is included in the database- how complete is the dataset?	All or almost all (>97%)
How and when was completeness of the registry last determined?	Monthly

What variables are included in the registry?	Identifier_condition_ intervention_ short term outcome or long term outcome_major known confounders
REGISTRY NAME	NSW Concord Colorectal Cancer Clinical Registry
Type of Registry	Care Management
What is the common circumstance that determines inclusion in the registry?	Resection for adenocarcinoma or colon and rectum.
What is the primary outcome collected by the registry?	Death, recurrence
Is there any bias associated with the outcome due to the way in which it was reported?	Independent observer not blinded to the intervention
What geographical area is covered by the registry?	South West Sydney Health Service- referral hospital for wider geographical area
Which group, if any, is not represented in the registry yet ought to be?	Larger population group
Have subjects given consent for data collection?	Subjects informed individually of data collection and use to which it will be put
What is the level to which subjects have consented?	Opt in- Signed consent obtained only on first contact with the service
Date in which data was first collected	1/01/1971
Number of individuals/ episodes of care included in the registry	4000 individuals
Date in which this was determined	1/04/2007
How is data collected?	Paper-based reporting
If the registry documents management of patients, for what period of time are individuals followed up?	15 years /death
If nationally approved codes are used to identify the subject, clinician or institution, what is link key?	Medical record number / hospital name
To which other database is linkage routinely undertaken	Administrative database within hospital
How are records stored on the database?	Identifiable
Is the registry endorsed by any clinical/professional association?	No
Was a Steering Committee established when the registry was developed?	No
Is a Management Committee supporting the registry	Yes
How often does the Management Committee meet?	Weekly
Have Terms of Reference been established with reporting processes to address issues	No
What is the source of funding for the registry?	No explicit funds
What proportion of the eligible population is included in the database- how complete is the dataset?	Most (90-97%)
How and when was completeness of the registry last determined?	ICD codes, pathology results, discussion with staff
What variables are included in the registry?	Identifier_condition_ intervention_ short term outcome_major known confounders_long term outcome

REGISTRY NAME	Australian Bleeding Disorder Registry
Type of Registry	Disease-specific
What is the common circumstance that determines inclusion in the registry?	Patients identified as having haemophilia and treated in any of fifteen treatment centres in Australia (not NSW)
What is the primary outcome collected by the registry?	Health of haemophilic population and product use. Death is an outcome measured however no data linkage to death index and no active follow up.
Is there any bias associated with the outcome due to the way in which it was reported?	Independent observer blinded to the intervention or not necessary as objective outcome
What geographical area is covered by the registry?	Fifteen treatment centres in Australia
Which group, if any, is not represented in the registry yet ought to be?	Haemophiliacs going to private hospitals/clinics
Have subjects given consent for data collection?	Subjects not informed explicitly
What is the level to which subjects have consented?	Opt off- Signed consent not obtained and no option to be removed from registry
Date in which data was first collected	1/01/1999
Number of individuals/ episodes of care included in the registry	3336 individuals
Date in which this was determined	30/06/2006
How is data collected?	Paper-based reporting
If the registry documents management of patients, for what period of time are individuals followed up?	Until patients stop coming to the treatment centre
If nationally approved codes are used to identify the subject, clinician or institution, what is link key?	N/A
To which other database is linkage routinely undertaken	Nil
How are records stored on the database?	Irreversibly anonymised
Is the registry endorsed by any clinical/professional association?	Haemophilia Association
Was a Steering Committee established when the registry was developed?	Yes
Is a Management Committee supporting the registry	Yes
How often does the Management Committee meet?	3 monthly
Have Terms of Reference been established with reporting processes to address issues	No
What is the source of funding for the registry?	Public sector(DHS/Uni)
What proportion of the eligible population is included in the database- how complete is the dataset?	All or almost all (>97%)
How and when was completeness of the registry last determined?	Comparison of haemophilic numbers with Canada population
What variables are included in the registry?	Identifier_condition_intervention_short term outcome_major known confounders_long term outcome

REGISTRY NAME	Victorian Infection Control Nosocomial Infection Surveillance System (VICNISS)
Type of Registry	Care Management
What is the common circumstance that determines inclusion in the registry?	Patients admitted to Victorian public hospitals for cardiac or orthopaedic surgery and patients diagnosed as having a laboratory-confirmed infection while in ICU. Surgical procedures including - cardiac, orthopedic, c section, colo-rectal and general surgical.
What is the primary outcome collected by the registry?	Healthcare associated infection
Is there any bias associated with the outcome due to the way in which it was reported?	Independent observer not blinded to the intervention
What geographical area is covered by the registry?	Victoria
Which group, if any, is not represented in the registry yet ought to be?	Private Hospitals, non acute hospitals
Have subjects given consent for data collection?	Subjects not informed explicitly
What is the level to which subjects have consented?	Opt off- Signed consent not obtained and no option to be removed from registry
Date in which data was first collected	1/11/2002
Number of individuals/ episodes of care included in the registry	44000 individuals
Date in which this was determined	30/08/2006
How is data collected?	Paper-based reporting
If the registry documents management of patients, for what period of time are individuals followed up?	Until discharge
If nationally approved codes are used to identify the subject, clinician or institution, what is link key?	Patient identifier
To which other database is linkage routinely undertaken	Nil
How are records stored on the database?	Reversibly anonymised
Is the registry endorsed by any clinical/professional association?	NO
Was a Steering Committee established when the registry was developed?	Yes
Is a Management Committee supporting the registry	Yes-Advisory Committee
How often does the Management Committee meet?	Quarterly, as required
Have Terms of Reference been established with reporting processes to address issues	Yes
What is the source of funding for the registry?	Public sector(DHS/Uni)
What proportion of the eligible population is included in the database- how complete is the dataset?	Most (90-97%)
How and when was completeness of the registry last determined?	Validated against hospital records.
What variables are included in the registry?	Identifier_condition_intervention_short term outcome or long term outcome_major known confounders

REGISTRY NAME	BreastScreen Victoria
Type of Registry	Surveillance
What is the common circumstance that determines inclusion in the registry?	Any woman over the age of 40 years who has a mammography in the BreastScreen Australia program.
What is the primary outcome collected by the registry?	Breast cancer
Is there any bias associated with the outcome due to the way in which it was reported?	Independent observer blinded to the intervention or not necessary as objective outcome
What geographical area is covered by the registry?	Victoria
Which group, if any, is not represented in the registry yet ought to be?	Under 40, women who have breast cancer in the past, women in high risk group
Have subjects given consent for data collection?	Subjects informed individually of data collection and use to which it will be put
What is the level to which subjects have consented?	Opt-in- Signed consent obtained for each episode of care
Date in which data was first collected	1/02/1992
Number of individuals/ episodes of care included in the registry	650000
Date in which this was determined	1/09/2006
How is data collected?	
If the registry documents management of patients, for what period of time are individuals followed up?	Until death
If nationally approved codes are used to identify the subject, clinician or institution, what is link key?	G.P. Person's identifiers (Name, address, DOB)
To which other database is linkage routinely undertaken	Victorian Electoral Commission (women between 50-69 years)
How are records stored on the database?	Identifiable
Is the registry endorsed by any clinical/professional association?	No
Was a Steering Committee established when the registry was developed?	Yes
Is a Management Committee supporting the registry	Yes
How often does the Management Committee meet?	Monthly
Have Terms of Reference been established with reporting processes to address issues	Yes
What is the source of funding for the registry?	Public sector(DHS/Uni)
What proportion of the eligible population is included in the database- how complete is the dataset?	Unknown or few (<80%)
How and when was completeness of the registry last determined?	Electoral Commission, Estimated Resident Population
What variables are included in the registry?	Identifier_condition_ intervention_ short term outcome_major known confounders_long term outcome

REGISTRY NAME	Australian National Creutzfeldt-Jakob Disease Registry
Type of Registry	Disease-specific
What is the common circumstance that determines inclusion in the registry?	Any person who has had suspected or confirmed diagnosis of CJD
What is the primary outcome collected by the registry?	Death
Is there any bias associated with the outcome due to the way in which it was reported?	Observer neither independent nor blinded to the intervention
What geographical area is covered by the registry?	Australia
Which group, if any, is not represented in the registry yet ought to be?	Nil
Have subjects given consent for data collection?	Subjects informed individually of data collection and use to which it will be put
What is the level to which subjects have consented?	Notifications to the ANCJDR arrive through various sources without consent. These can include referrals for diagnostic investigations, public health units reporting under notifiable disease legislation and searches from inpatient data
Date in which data was first collected	1/10/1993
Number of individuals/ episodes of care included in the registry	1160 individuals
Date in which this was determined	30/11/2006
How is data collected?	Paper-based reporting
If the registry documents management of patients, for what period of time are individuals followed up?	Until death or a clinical/pathological outcome achieved
If nationally approved codes are used to identify the subject, clinician or institution, what is link key?	
To which other database is linkage routinely undertaken	
How are records stored on the database?	Identifiable
Is the registry endorsed by any clinical/professional association?	Commonwealth and State Health Departments and Communicable Diseases Network Australia
Was a Steering Committee established when the registry was developed?	No
Is a Management Committee supporting the registry	
How often does the Management Committee meet?	
Have Terms of Reference been established with reporting processes to address issues	No
What is the source of funding for the registry?	Public sector(DHS/Uni)
What proportion of the eligible population is included in the database- how complete is the dataset?	Most (90-97%)
How and when was completeness of the registry last determined?	Cross checks of inpatient data sets, AIHW coded deaths (both annually) and mailouts to Australian Neurologists and Pathologists (semi-annually) to ensure all suspect and coded cases are identified
What variables are included in the registry?	Identifier_condition_ intervention_ short term outcome_major known confounders_long term outcome

REGISTRY NAME	Australian Bone Marrow Transplant Recipient Registry
Type of Registry	Disease-specific
What is the common circumstance that determines inclusion in the registry?	Any patient who has received a bone marrow transplant(haemopoietic stem cell transplant)
What is the primary outcome collected by the registry?	Mortality / Disease- free survival
Is there any bias associated with the outcome due to the way in which it was reported?	Independent observer blinded to the intervention or not necessary as objective outcome
What geographical area is covered by the registry?	Australia and New Zealand
Which group, if any, is not represented in the registry yet ought to be?	None
Have subjects given consent for data collection?	Subjects informed individually of data collection and use to which it will be put
What is the level to which subjects have consented?	Opt in- Signed consent obtained only on first contact with the service
Date in which data was first collected	1/01/1992
Number of individuals/ episodes of care included in the registry	14000 procedures
Date in which this was determined	1/07/2006
How is data collected?	Paper-based reporting
If the registry documents management of patients, for what period of time are individuals followed up?	Until death / loss to follow up
If nationally approved codes are used to identify the subject, clinician or institution, what is link key?	Date of birth, last name
To which other database is linkage routinely undertaken	National Death Index
How are records stored on the database?	Identifiable
Is the registry endorsed by any clinical/professional association?	Bone Marrow Transplants Society of Aust and NZ
Was a Steering Committee established when the registry was developed?	Yes
Is a Management Committee supporting the registry	No, informally
How often does the Management Committee meet?	6months
Have Terms of Reference been established with reporting processes to address issues	Yes
What is the source of funding for the registry?	Public sector(DHS/Uni)
What proportion of the eligible population is included in the database- how complete is the dataset?	All or almost all (>97%)
How and when was completeness of the registry last determined?	
What variables are included in the registry?	Identifier_condition_ intervention_ short term outcome_major known confounders_long term outcome

REGISTRY NAME	Australian Rheumatology Association Database Project	
Type of Registry	Disease-specific	
What is the common circumstance that determines inclusion in the registry?	Any Australian patient with an inflammatory rheumatic disease including those with: - Rheumatoid arthritis - Ankylosing spondylitis - Juvenile arthritis - Psoriatic arthritis It currently recruits patients commencing biologicals and collects health-related quality of life data and medical histories, and tracks short- and long-term safety and efficacy of arthritis therapy.	
What is the primary outcome collected by the registry?	Hlth risk-exposure to biological disease-modifying anti-rheumatic drugs	
Is there any bias associated with the outcome due to the way in which it was reported?	Independent observer not blinded to the intervention	
What geographical area is covered by the registry?	Australia	
Which group, if any, is not represented in the registry yet ought to be?	patients who do not receive biological therapy for inflammatory arthritis	
Have subjects given consent for data collection?	Subjects informed individually of data collection and use to which it will be put	
What is the level to which subjects have consented?	Opt in- Signed consent obtained only on first contact with the service	
Date in which data was first collected	1/08/2003	
Number of individuals/ episodes of care included in the registry	1065 individuals	N/A
Date in which this was determined	6/09/2006	
How is data collected?		
If the registry documents management of patients, for what period of time are individuals followed up?	6 monthly for 20 years or until death	
If nationally approved codes are used to identify the subject, clinician or institution, what is link key?	Patient identifiers	
To which other database is linkage routinely undertaken	Planned linkage with National Cancer Statistics Clearing House, National Death Index, Medicare Australia	
How are records stored on the database?	Identifiable	
Is the registry endorsed by any clinical/professional association?	Australia Rheumatology Association (ARA)	
Was a Steering Committee established when the registry was developed?	Yes	
Is a Management Committee supporting the registry	yes	
How often does the Management Committee meet?	Monthly	
Have Terms of Reference been established with reporting processes to address issues	No	
What is the source of funding for the registry?	Public sector(DHS/Uni)	
What proportion of the eligible population is included in the database- how complete is the dataset?	Unknown or few (<80%)	
How and when was completeness of the registry last determined?	currently being examined	
What variables are included in the registry?	Identifier_condition_ intervention_ short term outcome_major known confounders_long term outcome	

REGISTRY NAME	Victorian State Trauma Registry (VSTORM)	
Type of Registry	Care Management	
What is the common circumstance that determines inclusion in the registry?	All trauma patients with injury as principal diagnosis who meet inclusion criteria	
What is the primary outcome collected by the registry?	Morbidity and mortality following trauma	
Is there any bias associated with the outcome due to the way in which it was reported?	Independent observer blinded to the intervention or not necessary as objective outcome	
What geographical area is covered by the registry?	Patients treated within the Victorian state hospital trauma system	
Which group, if any, is not represented in the registry yet ought to be?	None known	
Have subjects given consent for data collection?	Subjects informed individually of data collection and use to which it will be put	
What is the level to which subjects have consented?	Opt off- Signed consent not obtained but option to be removed from registry	
Date in which data was first collected	1/07/2001	
Number of individuals/ episodes of care included in the registry	17772 individuals	21,540 episodes of care
Date in which this was determined	28/08/2006	
How is data collected?	Web-based reporting	
If the registry documents management of patients, for what period of time are individuals followed up?	6 months	
If nationally approved codes are used to identify the subject, clinician or institution, what is link key?	Last name, First name, DOB, Hospital UR number	
To which other database is linkage routinely undertaken	Coroners database; Death Registry	
How are records stored on the database?	Identifiable	
Is the registry endorsed by any clinical/professional association?	No	
Was a Steering Committee established when the registry was developed?	Yes	
Is a Management Committee supporting the registry	Yes	
How often does the Management Committee meet?	Quarterly	
Have Terms of Reference been established with reporting processes to address issues	Yes	
What is the source of funding for the registry?	Public sector(DHS/Uni)	
What proportion of the eligible population is included in the database- how complete is the dataset?	Unknown or few (<80%)	
How and when was completeness of the registry last determined?		
What variables are included in the registry?	Identifier_condition_intervention_short term outcome_major known confounders_long term outcome	

REGISTRY NAME	Trauma Registry. Royal Perth Hospital
Type of Registry	Care Management
What is the common circumstance that determines inclusion in the registry?	All trauma admissions that are admitted for more than 24 hours in an acute hospital. All injuries that occur within past 7 days.
What is the primary outcome collected by the registry?	Discharge
Is there any bias associated with the outcome due to the way in which it was reported?	
What geographical area is covered by the registry?	All patients admitted to Western Australian hospitals. Patients might be admitted from interstate or internationally (Bali)
Which group, if any, is not represented in the registry yet ought to be?	Patients not admitted -they go to other hospitals, death prior to arrival
Have subjects given consent for data collection?	Subjects not informed explicitly
What is the level to which subjects have consented?	Opt off- Signed consent not obtained and no option to be removed from registry
Date in which data was first collected	1/08/1994
Number of individuals/ episodes of care included in the registry	39000 individuals
Date in which this was determined	30/06/2006
How is data collected?	Paper-based reporting
If the registry documents management of patients, for what period of time are individuals followed up?	Until discharge
If nationally approved codes are used to identify the subject, clinician or institution, what is link key?	Patient identifiers - Account No./UMRN
To which other database is linkage routinely undertaken	Linked to TOPAS, patient administration system, theatre management system.
How are records stored on the database?	Identifiable, Log on ID required
Is the registry endorsed by any clinical/professional association?	Hospital executive, Health Department, Hospital Trauma Committee
Was a Steering Committee established when the registry was developed?	Yes
Is a Management Committee supporting the registry	Yes
How often does the Management Committee meet?	Every 2 months
Have Terms of Reference been established with reporting processes to address issues	Yes
What is the source of funding for the registry?	DOH
What proportion of the eligible population is included in the database- how complete is the dataset?	All or almost all (>97%)
How and when was completeness of the registry last determined?	Running queries through database, TOPAS compared to Emergency department information system. Done every month
What variables are included in the registry?	Identifier_condition_ intervention_ short term outcome or long term outcome_major known confounders

REGISTRY NAME	Melbourne Interventional Group Interventional Cardiology Registry
Type of Registry	Care Management
What is the common circumstance that determines inclusion in the registry?	All percutaneous Coronary interventions at one of participant sites
What is the primary outcome collected by the registry?	Procedure success Mortality/morbidity
Is there any bias associated with the outcome due to the way in which it was reported?	Independent observer not blinded to the intervention
What geographical area is covered by the registry?	Melbourne Metro and Geelong
Which group, if any, is not represented in the registry yet ought to be?	Minimal private
Have subjects given consent for data collection?	Subjects informed individually of data collection and use to which it will be put
What is the level to which subjects have consented?	Opt off- Signed consent not obtained but option to be removed from registry
Date in which data was first collected	1/04/2004
Number of individuals/ episodes of care included in the registry	4265 procedures
Date in which this was determined	30/08/2006
How is data collected?	Paper-based reporting
if the registry documents management of patients, for what period of time are individuals followed up?	30 days and at 12 months
If nationally approved codes are used to identify the subject, clinician or institution, what is link key?	Patient identifiers
To which other database is linkage routinely undertaken	Nil
How are records stored on the database?	Identifiable
Is the registry endorsed by any clinical/professional association?	No
Was a Steering Committee established when the registry was developed?	No
Is a Management Committee supporting the registry	Yes
How often does the Management Committee meet?	Every Three months
Have Terms of Reference been established with reporting processes to address issues	No
What is the source of funding for the registry?	Private sector (industry)
What proportion of the eligible population is included in the database- how complete is the dataset?	Unknown or few (<80%)
How and when was completeness of the registry last determined?	
What variables are included in the registry?	Identifier_condition_ intervention_ short term outcome_major known confounders_long term outcome

REGISTRY NAME	Australian and New Zealand Liver Transplantation Registry
Type of Registry	Disease-specific
What is the common circumstance that determines inclusion in the registry?	All people listed onto an active waiting list for liver transplant in Australia or New Zealand
What is the primary outcome collected by the registry?	Mortality/survival
Is there any bias associated with the outcome due to the way in which it was reported?	Independent observer blinded to the intervention or not necessary as objective outcome
What geographical area is covered by the registry?	Australia and New Zealand
Which group, if any, is not represented in the registry yet ought to be?	None
Have subjects given consent for data collection?	Subjects informed individually of data collection and use to which it will be put
What is the level to which subjects have consented?	Opt in- Signed consent obtained only on first contact with the service
Date in which data was first collected	1/01/1985
Number of individuals/ episodes of care included in the registry	2980 individuals
Date in which this was determined	4/09/2006
How is data collected?	Web-based reporting
If the registry documents management of patients, for what period of time are individuals followed up?	Until death
If nationally approved codes are used to identify the subject, clinician or institution, what is link key?	Patient identifiers
To which other database is linkage routinely undertaken	Nil
How are records stored on the database?	Reversibly anonymised
Is the registry endorsed by any clinical/professional association?	No
Was a Steering Committee established when the registry was developed?	Yes
Is a Management Committee supporting the registry	Heads of Units, Database Manager/custodian
How often does the Management Committee meet?	Annually-6months
Have Terms of Reference been established with reporting processes to address issues	Yes
What is the source of funding for the registry?	Public sector(DHS/Uni)
What proportion of the eligible population is included in the database- how complete is the dataset?	All or almost all (>97%)
How and when was completeness of the registry last determined?	01/01/2006, Cross Validated Hospital data
What variables are included in the registry?	Identifier_condition or intervention_short term outcome or long term outcome

REGISTRY NAME	South Australian Infection Control Surveillance database
Type of Registry	Care Management
What is the common circumstance that determines inclusion in the registry?	All patients with hospital-acquired infections, blood stream, multi-resistant organisms, any new acquisition
What is the primary outcome collected by the registry?	Infection
Is there any bias associated with the outcome due to the way in which it was reported?	Independent observer not blinded to the intervention
What geographical area is covered by the registry?	All metro hospitals and two rural hospitals (Private -public -16). MRSA since Sept 2001, BSI since 1997 in 7 teaching hospitals but now all hospitals contributing data, all HAI since 2003.
Which group, if any, is not represented in the registry yet ought to be?	Not all public and private hospitals (see geographic area covered)
Have subjects given consent for data collection?	Subjects not informed explicitly
What is the level to which subjects have consented?	Opt off- Signed consent not obtained and no option to be removed from registry
Date in which data was first collected	1/09/2001
Number of individuals/ episodes of care included in the registry	
Date in which this was determined	
How is data collected?	Paper-based reporting
If the registry documents management of patients, for what period of time are individuals followed up?	No follow up
If nationally approved codes are used to identify the subject, clinician or institution, what is link key?	Patient identifier
To which other database is linkage routinely undertaken	Nil
How are records stored on the database?	Identifiable
Is the registry endorsed by any clinical/professional association?	No
Was a Steering Committee established when the registry was developed?	Yes
Is a Management Committee supporting the registry	Yes
How often does the Management Committee meet?	6 weekly, surveillance 4 x year
Have Terms of Reference been established with reporting processes to address issues	Yes
What is the source of funding for the registry?	Public sector(DHS/Uni)
What proportion of the eligible population is included in the database- how complete is the dataset?	Unknown or few (<80%)
How and when was completeness of the registry last determined?	
What variables are included in the registry?	Identifier_condition or intervention

REGISTRY NAME	Centre for Healthcare Related Infection Surveillance and Prevention (CHRISP)
Type of Registry	Care Management
What is the common circumstance that determines inclusion in the registry?	All patients with hospital-acquired infections (bloodstream infections and surgical site infections) admitted to any of 23 public hospitals in Queensland. Occupational exposure to infection in healthcare workers also recorded on the registry.
What is the primary outcome collected by the registry?	Surgical Site Infection, Blood Stream Infection
Is there any bias associated with the outcome due to the way in which it was reported?	N/A
What geographical area is covered by the registry?	23 public hospitals in Queensland
Which group, if any, is not represented in the registry yet ought to be?	
Have subjects given consent for data collection?	Subjects not informed explicitly
What is the level to which subjects have consented?	Opt off- Signed consent not obtained and no option to be removed from registry
Date in which data was first collected	1/02/2001
Number of individuals/ episodes of care included in the registry	60078 individuals
Date in which this was determined	30/06/2005
How is data collected?	
If the registry documents management of patients, for what period of time are individuals followed up?	No follow up
If nationally approved codes are used to identify the subject, clinician or institution, what is link key?	Patient identifier
To which other database is linkage routinely undertaken	At a hospital level, linkage occurs with administrative dataset but not at central level
How are records stored on the database?	Reversibly anonymised
Is the registry endorsed by any clinical/professional association?	No
Was a Steering Committee established when the registry was developed?	Yes
Is a Management Committee supporting the registry	RPG-Representative participant group
How often does the Management Committee meet?	twice a year
Have Terms of Reference been established with reporting processes to address issues	Yes
What is the source of funding for the registry?	Public sector(DHS/Uni)
What proportion of the eligible population is included in the database- how complete is the dataset?	All or almost all (>97%)
How and when was completeness of the registry last determined?	
What variables are included in the registry?	Identifier_condition_intervention_short term outcome or long term outcome_major known confounders

REGISTRY NAME	Australian Motor Neuron Disease Registry
Type of Registry	Disease-specific
What is the common circumstance that determines inclusion in the registry?	All patients with either combined upper/lower motor neurone or lower motor neurone signs in the region of onset with combined upper and lower motor neurone signs in at least one other region: Bulbar, lumbar, cervical
What is the primary outcome collected by the registry?	Paul Talman contacted: yet to receive details
Is there any bias associated with the outcome due to the way in which it was reported?	
What geographical area is covered by the registry?	Australia
Which group, if any, is not represented in the registry yet ought to be?	Nil
Have subjects given consent for data collection?	Subjects informed individually of data collection and use to which it will be put
What is the level to which subjects have consented?	Opt in- Signed consent obtained only on first contact with the service
Date in which data was first collected	1/06/2004
Number of individuals/ episodes of care included in the registry	450 individuals
Date in which this was determined	1/02/2006
How is data collected?	
If the registry documents management of patients, for what period of time are individuals followed up?	From diagnosis until death
If nationally approved codes are used to identify the subject, clinician or institution, what is link key?	N/A
To which other database is linkage routinely undertaken	N/A
How are records stored on the database?	Irreversibly anonymised
Is the registry endorsed by any clinical/professional association?	Australian and New Zealand Association of Neurologists. Motor Neuron Association of Australia.
Was a Steering Committee established when the registry was developed?	Yes
Is a Management Committee supporting the registry	Yes
How often does the Management Committee meet?	
Have Terms of Reference been established with reporting processes to address issues	
What is the source of funding for the registry?	Unrestricted Educational Grant
What proportion of the eligible population is included in the database- how complete is the dataset?	Unknown or few (<80%) 40% of patients
How and when was completeness of the registry last determined?	Continuously
What variables are included in the registry?	0

REGISTRY NAME	Australian Orthopaedic Association Joint Replacement Registry
Type of Registry	Implant_Device
What is the common circumstance that determines inclusion in the registry?	All patients who undergo hip and knee joint replacement procedures in Australia.
What is the primary outcome collected by the registry?	Prosthesis revision surgery Prosthesis performance
Is there any bias associated with the outcome due to the way in which it was reported?	Independent observer blinded to the intervention or not necessary as objective outcome
What geographical area is covered by the registry?	Australia (Eligible pop: NSW 97%, Vic 91%, Qld 98%, WA 81%, SA 94%, Tas 90A%, ACT/NT 100%)
Which group, if any, is not represented in the registry yet ought to be?	
Have subjects given consent for data collection?	Subjects informed individually of data collection and use to which it will be put
What is the level to which subjects have consented?	Opt off- Signed consent not obtained but option to be removed from registry
Date in which data was first collected	1/09/1999
Number of individuals/ episodes of care included in the registry	300000
Date in which this was determined	1/10/2006
How is data collected?	
If the registry documents management of patients, for what period of time are individuals followed up?	Only if revision required
If nationally approved codes are used to identify the subject, clinician or institution, what is link key?	Last name, First name, DOB
To which other database is linkage routinely undertaken	National Death Index
How are records stored on the database?	Irreversibly anonymised
Is the registry endorsed by any clinical/professional association?	Australian Orthopaedic Association
Was a Steering Committee established when the registry was developed?	Yes
Is a Management Committee supporting the registry	Yes
How often does the Management Committee meet?	Weekly
Have Terms of Reference been established with reporting processes to address issues	Yes
What is the source of funding for the registry?	Public sector(DHS/Uni)
What proportion of the eligible population is included in the database- how complete is the dataset?	All or almost all (>97%)
How and when was completeness of the registry last determined?	Annually
What variables are included in the registry?	Identifier_condition_intervention_short term outcome_major known confounders_long term outcome

REGISTRY NAME	Australian Society of Cardiothoracic Surgeons Database Project	
Type of Registry	Care Management	
What is the common circumstance that determines inclusion in the registry?	All patients undergoing cardiothoracic surgery in contributing hospitals	
What is the primary outcome collected by the registry?	30 day mortality	
Is there any bias associated with the outcome due to the way in which it was reported?	Independent observer blinded to the intervention or not necessary as objective outcome	
What geographical area is covered by the registry?	Public hospitals in Vic, Some public hospitals in NSW 1 Private hospital in Qld 1 Private hospital in NSW 1 Public hospital in SA	
Which group, if any, is not represented in the registry yet ought to be?		
Have subjects given consent for data collection?	Subjects informed individually of data collection and use to which it will be put	
What is the level to which subjects have consented?	Opt off- Signed consent not obtained but option to be removed from registry	
Date in which data was first collected	1/07/2001	
Number of individuals/ episodes of care included in the registry	13400 procedures	
Date in which this was determined	30/06/2006	
How is data collected?	Paper-based reporting	
If the registry documents management of patients, for what period of time are individuals followed up?	30 days post procedure	
If nationally approved codes are used to identify the subject, clinician or institution, what is link key?	Medicare number, ICD codes for procedures	
To which other database is linkage routinely undertaken	Victorian Admitted Episodes Database (VAED)	
How are records stored on the database?	Identifiable	
Is the registry endorsed by any clinical/professional association?	Yes- ASCTS	
Was a Steering Committee established when the registry was developed?	Yes	
Is a Management Committee supporting the registry	Yes	
How often does the Management Committee meet?	Monthly	
Have Terms of Reference been established with reporting processes to address issues	Yes	
What is the source of funding for the registry?	Public sector(DHS/Uni)	
What proportion of the eligible population is included in the database- how complete is the dataset?	All or almost all (>97%)	
How and when was completeness of the registry last determined?	Currently being determined	
What variables are included in the registry?	Identifier_condition_intervention_short term outcome or long term outcome_major known confounders	

REGISTRY NAME	South Australian Trauma Registry
Type of Registry	Care Management
What is the common circumstance that determines inclusion in the registry?	All patients suffering severe physical trauma and managed in any one of six metropolitan hospitals.
What is the primary outcome collected by the registry?	Survival
Is there any bias associated with the outcome due to the way in which it was reported?	Independent observer blinded to the intervention or not necessary as objective outcome
What geographical area is covered by the registry?	Three major trauma services and three urban trauma services from within South Australia and North Territory
Which group, if any, is not represented in the registry yet ought to be?	
Have subjects given consent for data collection?	
What is the level to which subjects have consented?	Opt off- Signed consent not obtained but option to be removed from registry
Date in which data was first collected	1/01/1994
Number of individuals/ episodes of care included in the registry	28695 individuals
Date in which this was determined	2/08/2006
How is data collected?	Paper-based reporting
If the registry documents management of patients, for what period of time are individuals followed up?	No
If nationally approved codes are used to identify the subject, clinician or institution, what is link key?	Patient identifiers
To which other database is linkage routinely undertaken	Hospital admission database
How are records stored on the database?	Reversibly anonymised
Is the registry endorsed by any clinical/professional association?	No
Was a Steering Committee established when the registry was developed?	Yes
Is a Management Committee supporting the registry	yes
How often does the Management Committee meet?	Monthly, Quarterly
Have Terms of Reference been established with reporting processes to address issues	No
What is the source of funding for the registry?	Public sector(DHS/Uni)
What proportion of the eligible population is included in the database- how complete is the dataset?	Most (90-97%)
How and when was completeness of the registry last determined?	Based on severity of injury as captured by hospital administration database
What variables are included in the registry?	Identifier_condition_intervention_short term outcome or long term outcome_major known confounders

REGISTRY NAME	Victorian Cardiac Arrest Registry
Type of Registry	Care Management
What is the common circumstance that determines inclusion in the registry?	All patients suffering an out-of-hospital cardiac arrest who are attended by the ambulance service
What is the primary outcome collected by the registry?	Dead/Alive
Is there any bias associated with the outcome due to the way in which it was reported?	N/A
What geographical area is covered by the registry?	Victoria
Which group, if any, is not represented in the registry yet ought to be?	Mount Alexandra, no patient records
Have subjects given consent for data collection?	Subjects not informed explicitly, is not required
What is the level to which subjects have consented?	Opt off- Signed consent not obtained and no option to be removed from registry
Date in which data was first collected	1/10/1999
Number of individuals/ episodes of care included in the registry	31186 individuals
Date in which this was determined	6/10/2006
How is data collected?	Paper-based reporting
If the registry documents management of patients, for what period of time are individuals followed up?	Until discharge from hospital
If nationally approved codes are used to identify the subject, clinician or institution, what is link key?	N/A
To which other database is linkage routinely undertaken	Death Registry
How are records stored on the database?	Identifiable
Is the registry endorsed by any clinical/professional association?	Yes, Metropolitan Service Committee
Was a Steering Committee established when the registry was developed?	Yes
Is a Management Committee supporting the registry	yes
How often does the Management Committee meet?	fortnight
Have Terms of Reference been established with reporting processes to address issues	yes
What is the source of funding for the registry?	Public sector(DHS/Uni)
What proportion of the eligible population is included in the database- how complete is the dataset?	All or almost all (>97%)
How and when was completeness of the registry last determined?	tracking of No of cases, through database every month
What variables are included in the registry?	Identifier_condition_ intervention_ short term outcome_major known confounders_long term outcome

REGISTRY NAME:	Australian and New Zealand Dialysis and Transplantation Registry (ANZDATA)	
Type of Registry	Care Management	
What is the common circumstance that determines inclusion in the registry?	All patients receiving renal replacement treatment. This included those on dialysis and renal transplant patients	
What is the primary outcome collected by the registry?	Death, Function of the Transplant	
Is there any bias associated with the outcome due to the way in which it was reported?	Observer neither independent nor blinded to the intervention	
What geographical area is covered by the registry?	All dialysis units and transplantation services in Australia and New Zealand	
Which group, if any, is not represented in the registry yet ought to be?		
Have subjects given consent for data collection?	Subjects informed individually of data collection and use to which it will be put	
What is the level to which subjects have consented?	Opt off- Signed consent not obtained but option to be removed from registry	
Date in which data was first collected	1/01/1963	
Number of individuals/ episodes of care included in the registry	20000 individuals	4 1000 exposures
Date in which this was determined	1/10/2006	
How is data collected?	Web-based reporting	
If the registry documents management of patients, for what period of time are individuals followed up?	Until death / loss to follow up	
If nationally approved codes are used to identify the subject, clinician or institution, what is link key?	Last name, date of birth	
To which other database is linkage routinely undertaken	Organ donor database	
How are records stored on the database?	Identifiable	
Is the registry endorsed by any clinical/professional association?	Yes	
Was a Steering Committee established when the registry was developed?	Yes	
Is a Management Committee supporting the registry	Yes	
How often does the Management Committee meet?	Monthly	
Have Terms of Reference been established with reporting processes to address issues	No	
What is the source of funding for the registry?	Public sector(DHS/Uni)	
What proportion of the eligible population is included in the database- how complete is the dataset?	All or almost all (>97%)	
How and when was completeness of the registry last determined?		
What variables are included in the registry?	Identifier_condition_ intervention_ short term outcome_major known confounders_long term outcome	

REGISTRY NAME	Australian Corneal Graft Registry
Type of Registry	Implant_Device
What is the common circumstance that determines inclusion in the registry?	All patients receiving corneal graft transplantation
What is the primary outcome collected by the registry?	Graft Survival - Visual outcome
Is there any bias associated with the outcome due to the way in which it was reported?	Observer neither independent nor blinded to the intervention
What geographical area is covered by the registry?	Western Australia, South Australia, Victoria, New South Wales and Queensland
Which group, if any, is not represented in the registry yet ought to be?	
Have subjects given consent for data collection?	Subjects informed individually of data collection and use to which it will be put
What is the level to which subjects have consented?	Opt off- Signed consent not obtained but option to be removed from registry
Date in which data was first collected	1/01/1985
Number of individuals/ episodes of care included in the registry	18000 grafts for 14,000 patients
Date in which this was determined	1/08/2006
How is data collected?	Paper-based reporting
If the registry documents management of patients, for what period of time are individuals followed up?	Annually until death, loss of graft or loss to follow up
If nationally approved codes are used to identify the subject, clinician or institution, what is link key?	N/A
To which other database is linkage routinely undertaken	N/A
How are records stored on the database?	Reversibly anonymised
Is the registry endorsed by any clinical/professional association?	No
Was a Steering Committee established when the registry was developed?	No
Is a Management Committee supporting the registry	Yes
How often does the Management Committee meet?	Annually
Have Terms of Reference been established with reporting processes to address issues	No
What is the source of funding for the registry?	Public sector(DHS/Uni)
What proportion of the eligible population is included in the database- how complete is the dataset?	Most (90-97%)
How and when was completeness of the registry last determined?	
What variables are included in the registry?	Identifier_condition_ intervention_ short term outcome_major known confounders_long term outcome

REGISTRY NAME	Australian and New Zealand Cardiothoracic Organ Transplantation Registry
Type of Registry	Disease-specific
What is the common circumstance that determines inclusion in the registry?	All patients listed onto an active waiting list for heart-lung transplant in Australia or New Zealand
What is the primary outcome collected by the registry?	Death or initial instance of cancer
Is there any bias associated with the outcome due to the way in which it was reported?	Independent observer not blinded to the intervention
What geographical area is covered by the registry?	Australia and NZ
Which group, if any, is not represented in the registry yet ought to be?	None
Have subjects given consent for data collection?	Subjects informed collectively of data collection and use to which it will be put
What is the level to which subjects have consented?	Opt off- Signed consent not obtained but option to be removed from registry
Date in which data was first collected	1/01/1984
Number of individuals/ episodes of care included in the registry	3042 individuals
Date in which this was determined	31/12/2005
How is data collected?	Paper-based reporting
If the registry documents management of patients, for what period of time are individuals followed up?	Until death
If nationally approved codes are used to identify the subject, clinician or institution, what is link key?	Patient identifier
To which other database is linkage routinely undertaken	Organ Donor registry
How are records stored on the database?	Identifiable
Is the registry endorsed by any clinical/professional association?	Not formally. Supported through release of data
Was a Steering Committee established when the registry was developed?	No
Is a Management Committee supporting the registry	Yes
How often does the Management Committee meet?	Annually
Have Terms of Reference been established with reporting processes to address issues	No
What is the source of funding for the registry?	Public sector(DHS/Uni)
What proportion of the eligible population is included in the database- how complete is the dataset?	All or almost all (>97%)
How and when was completeness of the registry last determined?	Link with organ transplant registry
What variables are included in the registry?	Identifier_condition_ intervention_ short term outcome_ major known confounders_long term outcome

REGISTRY NAME	Victorian Orthopaedic Trauma Registry (VOTOR)
Type of Registry	Care Management
What is the common circumstance that determines inclusion in the registry?	All patients admitted to Royal Melbourne Hospital or Alfred Hospital with an orthopaedic injury
What is the primary outcome collected by the registry?	Morbidity, quality of life
Is there any bias associated with the outcome due to the way in which it was reported?	Independent observer not blinded to the intervention
What geographical area is covered by the registry?	Melbourne
Which group, if any, is not represented in the registry yet ought to be?	Private hospitals/more hospitals sites. All public+Private hospitals
Have subjects given consent for data collection?	Subjects informed individually of data collection and use to which it will be put
What is the level to which subjects have consented?	Opt off- Signed consent not obtained but option to be removed from registry
Date in which data was first collected	1/08/2003
Number of individuals/ episodes of care included in the registry	4200 individuals
Date in which this was determined	30/08/2006
How is data collected?	
If the registry documents management of patients, for what period of time are individuals followed up?	6-12 months
If nationally approved codes are used to identify the subject, clinician or institution, what is link key?	Hospital identifier
To which other database is linkage routinely undertaken	Alfred Trauma Registry VSTORM, operational databases
How are records stored on the database?	Identifiable
Is the registry endorsed by any clinical/professional association?	No
Was a Steering Committee established when the registry was developed?	Yes
Is a Management Committee supporting the registry	Yes
How often does the Management Committee meet?	Fortnightly
Have Terms of Reference been established with reporting processes to address issues	No
What is the source of funding for the registry?	Public sector(DHS/Uni)
What proportion of the eligible population is included in the database- how complete is the dataset?	All or almost all (>97%)
How and when was completeness of the registry last determined?	Cross reference with trauma systems. Orthopaedic ED reports
What variables are included in the registry?	Identifier_condition or intervention_short term outcome or long term outcome

REGISTRY NAME	Australian and New Zealand Burns Association (ANZBA) National Burns Registry
Type of Registry	Care Management
What is the common circumstance that determines inclusion in the registry?	All patients admitted to a Burns Unit with any burn
What is the primary outcome collected by the registry?	
Is there any bias associated with the outcome due to the way in which it was reported?	Observer neither independent nor blinded to the intervention
What geographical area is covered by the registry?	Sixteen burns units in Australia have been recruited; 9 currently contributing data
Which group, if any, is not represented in the registry yet ought to be?	Seven hospitals in Australia have burns units but are not currently submitting data.
Have subjects given consent for data collection?	Subjects informed individually of data collection and use to which it will be put
What is the level to which subjects have consented?	Opt off- Signed consent not obtained but option to be removed from registry
Date in which data was first collected	1/03/2005
Number of individuals/ episodes of care included in the registry	1780 individuals
Date in which this was determined	1/01/2007
How is data collected?	Paper-based reporting
If the registry documents management of patients, for what period of time are individuals followed up?	No
If nationally approved codes are used to identify the subject, clinician or institution, what is link key?	Hospital identifier
To which other database is linkage routinely undertaken	
How are records stored on the database?	Reversibly anonymised
Is the registry endorsed by any clinical/professional association?	Australian and New Zealand Burns Association
Was a Steering Committee established when the registry was developed?	Yes
Is a Management Committee supporting the registry	No
How often does the Management Committee meet?	
Have Terms of Reference been established with reporting processes to address issues	No
What is the source of funding for the registry?	Public sector(DHS/Uni)
What proportion of the eligible population is included in the database- how complete is the dataset?	Unknown or few (<80%)
How and when was completeness of the registry last determined?	
What variables are included in the registry?	Identifier_condition or intervention_short term outcome or long term outcome

REGISTRY NAME	Cervical Cytology Registry- Victoria	
Type of Registry	Surveillance	
What is the common circumstance that determines inclusion in the registry?	All pap tests performed in Victoria	
What is the primary outcome collected by the registry?	Abnormal cytology/ histology	
Is there any bias associated with the outcome due to the way in which it was reported?	Independent observer blinded to the intervention or not necessary as objective outcome	
What geographical area is covered by the registry?	Victoria	
Which group, if any, is not represented in the registry yet ought to be?		
Have subjects given consent for data collection?	Subjects informed collectively of data collection and use to which it will be put	
What is the level to which subjects have consented?	Opt off- Signed consent not obtained but option to be removed from registry	
Date in which data was first collected	1/01/1989	
Number of individuals/ episodes of care included in the registry	2,560,000	12560000
Date in which this was determined	30/11/2006	
How is data collected?		
If the registry documents management of patients, for what period of time are individuals followed up?	Until pap tests ceased	
If nationally approved codes are used to identify the subject, clinician or institution, what is link key?	Medicare	
To which other database is linkage routinely undertaken	Births, Deaths and Marriages, Cancer Registry	
How are records stored on the database?	Identifiable	
Is the registry endorsed by any clinical/professional association?	No	
Was a Steering Committee established when the registry was developed?	Yes	
Is a Management Committee supporting the registry	Yes	
How often does the Management Committee meet?	Quarterly	
Have Terms of Reference been established with reporting processes to address issues	Yes	
What is the source of funding for the registry?	Public sector(DHS/Uni)	
What proportion of the eligible population is included in the database- how complete is the dataset?	Many (80-89%)	
How and when was completeness of the registry last determined?	Comparison with National Health Survey and ABS	
What variables are included in the registry?	Identifier_condition_ intervention_ short term outcome_major known confounders_long term outcome	

REGISTRY NAME	Haemostasis Registry
Type of Registry	Disease-specific
What is the common circumstance that determines inclusion in the registry?	All non-haemophilic patients treated with recombinant activated factor VII
What is the primary outcome collected by the registry?	Cessation of Bleeding
Is there any bias associated with the outcome due to the way in which it was reported?	Observer neither independent nor blinded to the intervention
What geographical area is covered by the registry?	Australia and New Zealand
Which group, if any, is not represented in the registry yet ought to be?	N/A
Have subjects given consent for data collection?	Subjects not informed explicitly
What is the level to which subjects have consented?	Opt off- Signed consent not obtained and no option to be removed from registry
Date in which data was first collected	1/01/2005
Number of individuals/ episodes of care included in the registry	760
Date in which this was determined	25/10/2006
How is data collected?	Paper-based reporting
If the registry documents management of patients, for what period of time are individuals followed up?	28 days
If nationally approved codes are used to identify the subject, clinician or institution, what is link key?	N/A
To which other database is linkage routinely undertaken	N/A
How are records stored on the database?	Irreversibly anonymised
Is the registry endorsed by any clinical/professional association?	No
Was a Steering Committee established when the registry was developed?	Yes
Is a Management Committee supporting the registry	Yes
How often does the Management Committee meet?	6 monthly
Have Terms of Reference been established with reporting processes to address issues	Yes
What is the source of funding for the registry?	Private sector (industry)
What proportion of the eligible population is included in the database- how complete is the dataset?	Most (90-97%)
How and when was completeness of the registry last determined?	Compared with pharmaceutical company records
What variables are included in the registry?	Identifier_condition_intervention_short term outcome or long term outcome_major known confounders

REGISTRY NAME	Melbourne Vascular Surgeons Association Audit
Type of Registry	Care Management
What is the common circumstance that determines inclusion in the registry?	All arterial surgery analyzed for 1) Mortality after Aortic Aneurysm Repair 2) Stroke and death rate after Carotid endarterectomy 3) Graft occlusion rate after Lower limb bypass surgery
What is the primary outcome collected by the registry?	Mortality following vascular surgery and graft occlusion post lower limb surgery
Is there any bias associated with the outcome due to the way in which it was reported?	Observer neither independent nor blinded to the intervention
What geographical area is covered by the registry?	Greater Melbourne, Geelong and Ballarat
Which group, if any, is not represented in the registry yet ought to be?	
Have subjects given consent for data collection?	Subjects not informed explicitly
What is the level to which subjects have consented?	Opt off- Signed consent not obtained and no option to be removed from registry
Date in which data was first collected	1/01/1999
Number of individuals/ episodes of care included in the registry	42000 procedures
Date in which this was determined	12/10/2006
How is data collected?	Paper-based reporting
If the registry documents management of patients, for what period of time are individuals followed up?	Until discharge
If nationally approved codes are used to identify the subject, clinician or institution, what is link key?	Providers, however this is anonymised in registry - No Link
To which other database is linkage routinely undertaken	No data linkage performed
How are records stored on the database?	Irreversibly anonymised
Is the registry endorsed by any clinical/professional association?	Australasian College of Surgeons
Was a Steering Committee established when the registry was developed?	Yes
Is a Management Committee supporting the registry	Yes
How often does the Management Committee meet?	Monthly
Have Terms of Reference been established with reporting processes to address issues	No
What is the source of funding for the registry?	Public sector(DHS/Uni)
What proportion of the eligible population is included in the database- how complete is the dataset?	Many (80-89%)
How and when was completeness of the registry last determined?	Independent check 2004 of 5% sample
What variables are included in the registry?	Identifier_condition_intervention_short term outcome_major known confounders_long term outcome

REGISTRY NAME	Western Australian Pre-hospital Care Database
Type of Registry	Care Management
What is the common circumstance that determines inclusion in the registry?	All ambulance attendances in the Perth metropolitan area since 1990.
What is the primary outcome collected by the registry?	Cardiac arrest and long term outcome of patients being treated by the ambulance service
Is there any bias associated with the outcome due to the way in which it was reported?	
What geographical area is covered by the registry?	Perth metropolitan area
Which group, if any, is not represented in the registry yet ought to be?	
Have subjects given consent for data collection?	
What is the level to which subjects have consented?	
Date in which data was first collected	1/01/1990
Number of individuals/ episodes of care included in the registry	1,000,000 individuals
Date in which this was determined	30/06/2006
How is data collected?	Paper-based reporting
If the registry documents management of patients, for what period of time are individuals followed up?	
If nationally approved codes are used to identify the subject, clinician or institution, what is link key?	Patient identifiers
To which other database is linkage routinely undertaken	Western Australian Health Services Linked Database
How are records stored on the database?	
Is the registry endorsed by any clinical/professional association?	No
Was a Steering Committee established when the registry was developed?	
Is a Management Committee supporting the registry	
How often does the Management Committee meet?	
Have Terms of Reference been established with reporting processes to address issues	
What is the source of funding for the registry?	Public sector(DHS/Uni)
What proportion of the eligible population is included in the database- how complete is the dataset?	All or almost all (>97%)
How and when was completeness of the registry last determined?	
What variables are included in the registry?	Identifier_condition_ intervention_ short term outcome or long term outcome_major known confounders

REGISTRY NAME	Australian and New Zealand Intensive Care Unit Society (ANZICS) Adult Patient Database
Type of Registry	Care Management
What is the common circumstance that determines inclusion in the registry?	All admissions to intensive care units (ICU) and to units under the care umbrella of the ICU
What is the primary outcome collected by the registry?	Mortality
Is there any bias associated with the outcome due to the way in which it was reported?	Outcome not included
What geographical area is covered by the registry?	In 2006, 130 ICUs contributed to the database. This includes three Hongkong sites, nine NZ sites and the remaining 118 Australian sites. Since 2001, data has been received from 147 sites. Four of these ICUs have since closed. Thirteen are still open but have not contributed recently.
Which group, if any, is not represented in the registry yet ought to be?	Poor contribution from NZ. Private hospital contrib.
Have subjects given consent for data collection?	Subjects not informed explicitly
What is the level to which subjects have consented?	Opt off- Signed consent not obtained and no option to be removed from registry
Date in which data was first collected	1/01/1992
Number of individuals/ episodes of care included in the registry	636000 individuals
Date in which this was determined	30/08/2006
How is data collected?	
If the registry documents management of patients, for what period of time are individuals followed up?	Until hospital discharge
If nationally approved codes are used to identify the subject, clinician or institution, what is link key?	Patient identifiers, hospital
To which other database is linkage routinely undertaken	None Undertaken
How are records stored on the database?	Reversibly anonymised
Is the registry endorsed by any clinical/professional association?	Yes- Aust NZ Int Care Society, METeOR (AIHW)
Was a Steering Committee established when the registry was developed?	Yes
Is a Management Committee supporting the registry	Yes
How often does the Management Committee meet?	3 times per year
Have Terms of Reference been established with reporting processes to address issues	Yes
What is the source of funding for the registry?	Public sector(Government agencies of States,
What proportion of the eligible population is included in the database- how complete is the dataset?	Unknown or few (<80%)
How and when was completeness of the registry last determined?	
What variables are included in the registry?	Identifier_condition_ intervention_ short term outcome or long term outcome_major known confounders

REGISTRY NAME	ACCORD Comprehensive Cancer Patient Database
Type of Registry	Disease-specific
What is the common circumstance that determines inclusion in the registry?	A comprehensive cancer outcome registry containing a minimum dataset across all tumour types (brain, breast, colorectal, haematological malignancies, lung, melaoma, prostate) presenting to any of five collection sites
What is the primary outcome collected by the registry?	Cancer remission or recurrence/ death
Is there any bias associated with the outcome due to the way in which it was reported?	Independent observer blinded to the intervention or not necessary as objective outcome
What geographical area is covered by the registry?	Royal Melbourne Hospital, Western Hospital, Austin and Peter McCallum Hospitals, Box Hill
Which group, if any, is not represented in the registry yet ought to be?	More hospitals overall managing cancer patients
Have subjects given consent for data collection?	Subjects informed collectively of data collection and use to which it will be put
What is the level to which subjects have consented?	Opt off- Signed consent not obtained but option to be removed from registry
Date in which data was first collected	1/01/2003
Number of individuals/ episodes of care included in the registry	7000
Date in which this was determined	14/07/2007
How is data collected?	Web-based reporting and paper based reporting
If the registry documents management of patients, for what period of time are individuals followed up?	Until not presenting to hospital/ death
If nationally approved codes are used to identify the subject, clinician or institution, what is link key?	Medicare number, Hospital UR number
To which other database is linkage routinely undertaken	Victorian Cancer registry
How are records stored on the database?	Identifiable
Is the registry endorsed by any clinical/professional association?	Colorectal Surgical Society
Was a Steering Committee established when the registry was developed?	Yes
Is a Management Committee supporting the registry	Yes
How often does the Management Committee meet?	2 monthly
Have Terms of Reference been established with reporting processes to address issues	No, not formalised
What is the source of funding for the registry?	Public sector(DHS/Uni)
What proportion of the eligible population is included in the database- how complete is the dataset?	Most (90-97%)
How and when was completeness of the registry last determined?	Compared with the Cancer registry
What variables are included in the registry?	Identifier_condition_ intervention_ short term outcome_major known confounders_long term outcome

Appendix A

Registry of Registries Database Questionnaire

Unique ID

--	--



Centre of
Research Excellence
in Patient Safety

NHMRC Centre of Research Excellence in Patient Safety

Register of Registries Data dictionary + survey form

Registry/database title _____

Modified from the Directory of Clinical Databases (doCDat) located at the:

Health Services Research Unit,
Department of Public Health and Policy,
London School of Hygiene and Tropical Medicine,
London, United Kingdom

Black N, Payne M. Directory of Clinical Databases: improving and promoting their use.
Quality and Safety in Health Care_ 2003;12:348-352.

1. Table of contents

1. TABLE OF CONTENTS	2
2. PROJECT DETAILS	4
2.1. CONTACT INFORMATION.....	4
2.1.1. Database name	4
2.1.2. Database Head (name).....	4
2.1.3. Database administrator title	4
2.1.4. Contact person	4
2.1.5. Contact person title	4
2.1.6. Location of register.....	4
2.1.7. Name of primary contact person (if different from administrator).....	4
2.1.8. Phone number of primary contact person	4
2.1.9. Address for mailing.....	4
2.1.10. Email addresss	4
3. GENERAL ASPECTS	5
3.1. BACKGROUND INFORMATION	5
3.2. CONTACT DETAILS FOR REGISTRY CUSTODIAN/MANAGER	5
3.3. REFERENCE POPULATION	5
3.3.1. Common circumstance that determines inclusion in the database	5
3.3.2. Does the database trace individuals through more than one episode of care?	6
3.4. GEOGRAPHICAL AREA COVERED BY THE DATABASE	6
4. TIME PERIOD COVERED BY DATABASE	7
4.1. FOLLOW UP.....	7
5. DATA SET	8
5.1. CONTENT	8
5.1.1. Number of individuals or episodes of care included in the database	8
5.1.2. Date determined	8
5.1.3. Please provide an example of the data collection questionnaire	8
5.2. DATA LINKAGE.....	9
5.2.1. Are nationally approved codes used for identifying the subject, clinician or institution?	9
5.2.2. To which other databases is linkage routinely undertaken?.....	10
5.3. SECURITY	10
5.3.1. Where are the electronic data held?.....	10
5.3.2. Where is a back-up version of the electronic data held?	10
5.3.3. What happens to paper forms?.....	11
5.4. CONFIDENTIALITY	11
5.4.1. How are records stored on the database?.....	11
5.4.2. Have subjects given consent for data collection?.....	12
5.4.3. What is the level to which subjects have consented?	12
6. OUTPUTS	14
6.1. ANALYSIS	14
6.1.1. How frequently are data transferred from health care providers to the central database?.....	14
6.1.2. Can ad hoc analyses be performed for health care providers?	14
6.2. AUDIT REPORTS	15
6.2.1. How frequently are multi-centre audit reports produced?	15
6.2.2. How frequently are provider-specific audit reports produced?	15
6.3. PROVIDE A LIST OF PUBLICATIONS.....	16
7. MANAGEMENT	16
7.1. IS THE DATABASE APPROVED BY ANY CLINICAL OR PROFESSIONAL ASSOCIATIONS?.....	16
7.2. WHO IS INVOLVED IN THE MANAGEMENT OF THE DATABASE?	17

7.3.	GOVERNANCE.....	17
7.4.	SOURCE OF FUNDING:	18
8.	DATA QUALITY	18
8.1.	COVERAGE	18
8.1.1.	<i>Extent to which the eligible population is representative of the country.....</i>	<i>18</i>
8.1.2.	<i>What states/countries are represented in the database?</i>	<i>19</i>
8.1.3.	<i>Which group/s, if any, should be represented but is not?</i>	<i>19</i>
8.2.	COMPLETENESS OF RECRUITMENT OF ELIGIBLE POPULATION	19
8.2.1.	<i>How and when completeness last determined.....</i>	<i>20</i>
8.3.	VARIABLES INCLUDED IN THE DATABASE	20
8.4.	COMPLETENESS OF DATA (% VARIABLES AT LEAST 95% COMPLETE)	21
8.4.1.	<i>When was completeness last determined</i>	<i>21</i>
8.5.	FORM IN WHICH CONTINUOUS DATA (EXCLUDING DATES) IS COLLECTED	22
8.6.	USE OF EXPLICIT DEFINITIONS FOR VARIABLES	22
8.7.	USE OF EXPLICIT RULES FOR DECIDING HOW VARIABLES ARE RECORDED	22
8.8.	RELIABILITY OF CODING OF CONDITIONS AND INTERVENTIONS	23
8.8.1.	<i>How and when last tested</i>	<i>24</i>
8.9.	INDEPENDENCE OF OBSERVATIONS OF PRIMARY OUTCOME	24
8.9.1.	<i>Primary outcome</i>	<i>24</i>
8.10.	EXTENT TO WHICH DATA ARE VALIDATED	25
8.10.1.	<i>How last determined</i>	<i>26</i>
9.	CLASSIFICATION.....	26
9.1.	CLASSIFICATION – BODY SYSTEM	26
9.2.	CLASSIFICATION – PATHOGENESIS (UNDERLYING DISEASE PROCESS)	26
9.3.	CLASSIFICATION – INTERVENTION	27
9.4.	CLASSIFICATION – COUNTRY	27

2. Project details

2.1. Contact information

2.1.1. Database name _____

2.1.2. Database Head (name) _____

2.1.3. Database administrator title _____

2.1.4. Contact person _____

2.1.5. Contact person title _____

2.1.6. Location of register _____

2.1.7. Name of primary contact person (if different from administrator) _____

2.1.8. Phone number of primary contact person _____

2.1.9. Address for mailing _____

2.1.10. Email address _____

3. General aspects

3.1. *Background information*

Definition:

This section provides the user with a general overview of what the database covers, how it links with other databases, and any notable features.

3.2. *Contact details for registry custodian/manager*

Name and title of contact person for the Registry

Mailing address for correspondence

Electronic address for correspondence

3.3. *Reference population*

3.3.1. *Common circumstance that determines inclusion in the database*

Definition:

The characteristic that determines which individuals are included in the database. For example, all individuals who have undergone an operation to implant a heart valve, all people registered with a GP, or all individuals with a particular condition.

Rationale:

This question explores the scope of the database by defining exactly who is included, and therefore the population for which results from the data are generalisable. For example, if the database includes individuals with diabetes treated by a hospital specialist, the results may not be generalisable to all individuals with diabetes in the general population.

Response:

3.3.2. Does the database trace individuals through more than one episode of care?

Definition:

Is information collected about more than one episode of care for the same individual? For example, is the patient followed from the initial consultation with an oncologist, through to surgery, and then to rehabilitation (tracing through more than one episode of care), or is information only recorded for one episode of care (i.e. only the surgical operation is recorded)?

It must be possible for one patient's different episodes of care to be linked together (i.e. through the use of a unique patient id number). If the database collects information about different episodes of care, but does not link the patient across them, then the results will display 'No'.

An episode of care is defined as one contact with health services. This could include a visit to a GP, a surgical operation, an attendance at Accident and Emergency, or admission to Intensive Care. What constitutes an episode of care will therefore be dependant upon the condition being studied.

Rationale:

Databases that trace patients through more than one episode of care may contain more information about the patients' diagnosis, treatment and outcome, than databases that, for example, only collect information about the intervention. Furthermore, as the data are collected in the temporal sequence in which the events occur, the nature of the relationship between these events can be examined.

Response/notes:

3.4. *Geographical area covered by the database*

Definition:

This could be a group of countries (e.g. Australia and New Zealand), a single country (e.g. Australia), or a state or territory (e.g. Victoria).

Rationale:

This question explores the scope of the database, and provides information as to how generalisable the data from the database are. For example, if data are only collected from one hospital in New South Wales, the population of this hospital may not be representative of the whole of the Australian population. Question A of the Data Quality Assessment provides a measure of how representative the database is of the wider population.

Response/notes:

4. Time period covered by database

Definition:

Start date: The date (month and year) when data that are available and useful for analysis started to be collected (i.e. excluding pilot studies).

End date/ongoing: The date when such data ceased to be collected, or ongoing if data are still being collected.

Definition:

Continuous: Databases that recruit individuals for inclusion in the database continuously from when recruitment first started.

Periodic: Databases that recruit individuals for inclusion in the database over set periods, with gaps in recruitment between periods. For example, three months repeated every year.

One-off: Databases that recruit individuals for inclusion in the database for one limited period.

Rationale:

This question allows the user to see how individuals are recruited over time, and therefore the level of temporal information gained from that database.

For example, databases that continuously recruit individuals provide an uninterrupted picture of events during that period, ensuring that no information is lost and any analyses are as comprehensive as possible. Periodic databases provide 'snap-shot' data over time, and the results may be generalised (with caution), to cover the whole of the period that recruitment spans. Databases with one-off recruitment can only provide information relating to one period, and thus caution must be taken when generalising these results to other periods.

Start date

End date (if project no longer collects data)

Notes:

4.1. Follow up

Definition:

If the registry involves management of patients following a procedure, for what period of time are individuals followed up.

Rationale:

Often databases do not collect data post discharge from an acute care institution eg hospital. Those following up patients for extended time periods provide a more complete picture of outcome.

Period of follow up

Notes: _____

4.1.1. What database/s, if any, are used to assist with follow up?

Response/Notes: _____

5. Data set

5.1. Content

5.1.1. Number of individuals or episodes of care included in the database

Definition:

The number of individuals (e.g. unique patient records) or episodes of care (e.g. consultations, operations or admissions) included in the data set that are available for analysis.

Number of Individuals / episodes of care (circle)

5.1.2. Date determined

Definition:

The month and the year when the number was determined. For real time databases where entries are made to the database on a very regular basis, the size of the database will include all records entered up to that time. However, if the database receives data in batches (for example every six months), then the number of records will only be valid up to the last time data were added.

Rationale:

This lets the user know how up to date the number of records on the database is. For example, if the total number of records was only known for 6 months ago, the database may now include more records.

Date determined

Notes: _____

5.1.3. Please provide an example of the data collection questionnaire

Definition:

A PDF file of or web link to the questionnaire/s used to collect the data contained in the

database, or a complete list of variables included in the database if all data are collected electronically.

Rationale:

This provides the user with a complete list of all the data collected by the database, enabling the user to determine to what uses the data can be put, or whether the database is suitable for their needs. It is also important to know the exact way in which questions are worded when analysing data, as the way a question is phrased will influence the responses to that question.

Notes (include webpage if it can be downloaded)

5.2. Data linkage

5.2.1. Are nationally approved codes used for identifying the subject, clinician or institution?

Definition:

Does the database use nationally approved codes, e.g. the Department of Health in England and Wales to identify the subject, clinician, or institution?

For example, the nationally approved codes for Australia are as follows: Subject: Medicare number. Clinician: Provider number.

Rationale:

Use of these standard codes allows databases to link together for a number of different purposes. For example, information could be gathered from different databases about the same individual to provide a more complete picture of patient care (e.g. linking an administrative database with a specialised clinical one).

Circle if applicable:

Subject: Medicare number

Clinician: Provider number

Institution: Named hospital

Notes: _____

5.2.2. To which other databases is linkage routinely undertaken?

Definition:

The names of other databases with which the database routinely links to provide more information about subjects on the database. One-off linkages to other databases which do not form part of the standard procedure for the databases (for example to conduct a specific research project) are not included.

Rationale:

Shows what linkages are operating on a regular basis and thus what additional information is available.

Names of databases: _____

5.3. Security

5.3.1. Where are the electronic data held?

Definition:

Stand alone computer (not networked): Data are held on a computer that is not connected to any other computers via a modem or network. Such computers cannot be hacked into externally, and the actual hard drive of the computer would have to be stolen for the security of the data to be compromised.

Computer networked to an internal network: Data held on computer which is networked within the institution and backed up onto a server.

Computer connected to an external network: Data are held on a computer connected to the outside world via a modem or network connection, and are therefore potentially vulnerable to hacking despite the presence of firewalls, passwords, or other security measures.

Rationale:

Databases containing patient identifiable information must be held securely.

Notes: _____

5.3.2. Where is a back-up version of the electronic data held?

Definition:

Stand alone computer (not networked): Back-up data are saved on a computer that is not connected to any other computers via a modem or network. Such computers cannot be hacked into externally, and the actual hard drive of the computer would have to be stolen for the security of the data to be compromised.

Computer connected to an external network: Back-up data are held on a computer

connected to the outside world via a modem or network connection, and are therefore potentially vulnerable to hacking despite the presence of firewalls, passwords, or other security measures.

Data saved onto back-up disks: Back-up data are saved at regular intervals onto CD, floppy, Zip disk, or other storage device, and are stored securely.

No back-up version: No back-ups are made.

Rationale:

It is important to save back-up versions of the data to ensure that the data are not lost and to ensure that these back-up data are secure.

Notes: _____

5.3.3. What happens to paper forms?

Definition:

Paper questionnaires or forms containing information on individuals are kept and stored.

Paper questionnaires or forms are destroyed, or paper records are not kept as all data are collected electronically.

Rationale:

Stored paper forms pose a security risk as they could be stolen. Destroying or not collecting paper records is often a greater level of security.

Notes: _____

5.4. Confidentiality

5.4.1. How are records stored on the database?

Definition:

Identifiable: Individuals can be identified as one or more of the following are included: name, address, postcode, date of birth, Medicare number.

Reversibly anonymised: Individual identifiers (see above) have been removed or encrypted so those using the data cannot identify individuals. A unique individual ID (or 'key code') may be included. It is therefore possible to reverse the anonymisation of the data either by decrypting the encoded individual identifiers or by linking the data, through the 'key code', to individual identifiers.

Irreversibly anonymised: No individual identifiers or 'key codes' are stored on the database, or encryption is irreversible.

Rationale:

This question establishes the level of privacy and confidentiality of the data.

Notes: _____

5.4.2. Have subjects given consent for data collection?

Definition:

The procedure for obtaining subject consent as recommended by the central database.

- Signed consent obtained for each episode of care: Subjects sign a form at each episode of care, consenting to data about them being collected for that episode of care.
- Signed consent obtained only on first contact with service: Subjects sign a consent form giving their permission for data about them to be collected for that episode of care, and for any subsequent episode of care.
- Signed consent not obtained but option to opt out: Subjects are not asked to sign a consent form, but they are given the option to opt-out from inclusion on the database.
- Signed consent not obtained and no option to opt out: Subjects are not asked to sign a consent form, and are not given the option to opt-out from inclusion on the database.

Rationale:

How well does the database meet privacy and confidentiality requirements?

Notes: _____

5.4.3. What is the level to which subjects have consented?

Definition:

The procedure for informing subjects as recommended by the central database.

- Subjects informed individually of data collection and use to which data will be put: The subject has been informed that data will be collected about them, stored on a database, and used for particular purposes. Informing subjects can occur through a one-to-one discussion with the person collecting the data (usually the treating clinician), and/or via a printed information sheet.
- Subjects informed collectively of data collection and use to which data will be put: The subject has been informed that data will be collected about them, stored on a database, and used for particular purposes. Informing subjects occurs, for example, through posters and leaflets displayed at the location of the health care provider.
- Subjects not informed explicitly: No attempt is made to inform subjects that data will be stored on database and will be used.

Rationale:

How well does the database meet privacy and confidentiality requirements?

Notes: _____

6. Outputs

6.1. Analysis

6.1.1. How frequently are data transferred from health care providers to the central database?

Definition:

The frequency with which data are sent to the central database from the health care providers who collect the data. If data are automatically sent to the central database as soon as it is entered into the local system, the database is classified as a real time database.

Rationale:

A database which contains timely data can be used to analyse immediate changes, for example day-to-day changes in health care provision. In contrast, databases which infrequently collate and analyse their data can only be used for historical analyses.

- Daily
- Monthly
- Quarterly
- Annually
- Not transferred
- Other

Notes

6.1.2. Can ad hoc analyses be performed for health care providers?

Definition:

Locally:

Y = The health care provider who collects the data locally is able to analyse their data, even though their data are also sent to the centralised database to be analysed with the data collected from other health care providers.

N = Those who collect data locally cannot analyse their own data.

Not applicable = The data are not collected at local level and then submitted to central database but collected from multiple sources by the central database.

Centrally:

Y = Local health care providers can obtain ad hoc analyses of their own data from the central database custodian.

N = The people who collect data locally cannot obtain ad hoc analyses of their own data from the central database custodian.

Not applicable = The database only collects data from one health care provider, therefore only local analyses can be carried out

Rationale:

Data are often of better quality if those collecting them are involved in using/analysing them. By allowing data to be analysed at the local level as well, not only is better use made of that data, but the data are likely to be of better quality.

Notes: _____

6.2. *Audit reports*

6.2.1. How frequently are multi-centre audit reports produced?

Definition:

How often standard audit reports such as annual or quarterly reports, are produced by the central database. This may be the standard annual or quarterly report which is sent out to all providers and other interested parties, such as funders.

Rationale:

The frequency with which reports are produced gives an estimation of how rapidly, and to whom, results are disseminated.

- Monthly
- Quarterly
- Annually
- No reports have been produced
- Other

Notes: _____

6.2.2. How frequently are provider-specific audit reports produced?

Definition:

How often standard audit reports, are produced by the central database for individual health care providers who submit data to the database. These may contain only the results of the analysis of the data from that provider, or include comparisons with other providers.

Rationale:

The frequency with which reports are produced gives an estimation of how rapidly, and to whom, results are disseminated.

- Monthly
- Quarterly
- Annually
- No reports have been produced
- Other

Notes: _____

6.3. Provide a list of publications

Bibliography

Definition:

A PDF file of or web link to a bibliography listing published papers and reports produced using data from the database.

Rationale:

This gives an indication of how productive the database has been. It also provides the user with more information should they wish to find out more about the database.

Tick if publication list has been sent

If available on website, state website address: _____

7. Management

7.1. Is the database approved by any clinical or professional association?

Definition:

The clinical or professional bodies that have formally approved the database, for example by recommending that their members participate.

Rationale:

A database with such support is more likely to be promoted and therefore more widely used, and may receive financial backing, making it more stable.

Response/notes:

7.2. Who is involved in the management of the database?

Definition:

A list of the different disciplines and people whose skills are involved in the regular management of the database (NOT in the data collection).

Rationale:

Databases that are managed by a multi-disciplinary team generally produce better quality data, as they can draw on the expertise of different disciplines.

- Doctors
 - Nurses
 - Allied Health professionals (physiotherapists, psychologists)
 - Epidemiologist
 - Statistician
 - IT specialist
 - General Manager
 - Lay people
 - Others (please note): _____
- _____
- _____
- _____

7.3. Governance

Definition:

This section discusses processes in place to govern the database

Yes No

- A Steering Committee was involved in the establishment of the Registry
- A Management group oversees activities of the Registry

If yes to a Management group,

- how often do they meet?

- Are there Terms of Reference for its function/reporting structure

Is there a pathway for escalating issues identified by the Registry? For example, if it is evident that one institution is demonstrating poorer than average outcomes over an extended period of time will this get reported to anyone?

If there is a pathway, to whom is information reported? _____

Rationale:

This question allows the user to see how organised and structured registries are, and therefore the processes to ensure registries act responsibly to govern practice.

7.4. Source of funding:

Definition:

The sources of funds for the central database. These are classified as five main types:

- Public sector funding body (e.g. Dept of Human Services, Department of Health, university)
- Private sector (e.g. industry)
- Charity
- Membership subscription
- Research grant
- No explicit funds

Notes: _____

8. Data quality

8.1. Coverage

8.1.1. Extent to which the eligible population is representative of the country

Definition:

The extent to which the eligible population (defined by the common circumstance that determines inclusion and the geographical area covered by the database) can be generalised to the reference population (everyone with the common circumstance in the country from which the data are drawn).

- Level 1: No evidence or unlikely to be representative.
 - The sample is unlikely to be representative if those included represent a sub group (e.g. private patients/patients from one ethnic group).
- Level 2: Some evidence that eligible population is representative.
 - Basic comparisons have been made with the reference population (all those in the country with the common circumstance) which show that, for example, incidence rates or the socio-demographic distribution of the eligible population and the total population of the country are similar.
- Level 3: Good evidence the eligible population is representative.
 - Comparisons between the eligible population and the reference population show similar characteristics such as demographics or incidence.
 - A sampling frame has been used that captures a representative sample.
- Level 4: Total population of country included.
 - Every individual who has the common circumstance that determines inclusion (e.g. a heart valve operation) in the country from which data are collected (e.g.

Australia), is included in the database.

Rationale:

The more representative the sample in the database, the more the results from any analysis will represent the reference population with that common circumstance.

8.1.2. What states/countries are represented in the database?

Definition:

The states/countries that represent/s the total population. For example, for a database which covers two states, the country would be Australia, while for one that covered Australia and New Zealand the 'country' would be Australia/NZ.

- State: _____
- Australia
- New Zealand
- Other country/ies

Notes: _____

8.1.3. Which group/s, if any, should be represented but is/are not?

Definition:

This might include such groups as private hospitals, specific sub-groups such as ethnic groups.

Notes: _____

8.2. Completeness of recruitment of eligible population

Definition:

The proportion of the eligible population that the database includes. This can be determined by comparing the database with an external data source (such as surgical theatre books or hospital admission records) listing all of the individuals that the database aims to include.

- Level 1: Unknown or few (<80%)
- Level 2: Many (80-89%)
- Level 3: Most (90-97%)
- Level 4: All or almost all (>97%)

Rationale:

If a significant proportion of the population the database seeks to include are not captured

by the database, selection bias may be introduced whereby those included are systematically different from those who are not included in the sample. Selection bias reduces the generalisability of the results to the reference population.

Response/notes:

8.2.1. How and when completeness last determined

Definition:

The method by which completeness was determined (e.g. by comparing database records with hospital records), and the date (month and year) when it was last done.

Methods of determination of completeness of recruitment

Date at which this was last performed?

8.3. Variables included in the database

Definition:

Identifier: variables by which an individual/episode can be identified, e.g. name, address, postcode, date of birth, Medicare number, or other unique ID number.

Admin info: administrative information such as date of admission into hospital, date of operation, treating clinicians' code, and institution code.

Condition: primary diagnosis, e.g. breast cancer or diabetes. This will often be the common circumstance that determines inclusion.

Intervention: the intervention aimed at treating the condition e.g. surgery or drugs prescribed.

Short term outcome: the outcome at the end of that episode of care, e.g. post-operative outcome, status at discharge.

Major, known confounders: this will vary by condition, but generally would include comorbidity and age. It could also include socio-demographic variables such as socioeconomic status, behavioural variables such as smoking, and physiological variables such as height, weight and blood pressure. These variables are vital for producing risk-adjusted outcome analyses.

Long term outcome: this will vary according to the condition, but generally would include any follow-up of the patient/episode after the immediate outcome of the intervention (e.g. six months or a year after the first intervention, depending on the severity of the condition).

- Level 1: Identifier, condition or intervention.
- Level 2: Identifier, condition or intervention, short term outcome or long term outcome.
- Level 3: Identifier, condition, intervention, short term outcome or long term outcome, major known confounders.
- Level 4: Identifier, condition, intervention, short term outcome, major known confounders, long term outcome.

Rationale:

This gives the scope of analyses which can be conducted using the data. For example, if only an identifier and condition are recorded (as in a disease register), the data can be used for calculating incidence or prevalence of the condition, but no risk-adjusted outcomes analysis can be conducted. A long or short-term outcome, and the major known confounders are needed for this.

8.4. Completeness of data (% variables at least 95% complete)

Definition:

The percentage of variables at least 95% complete. The total number of variables at least 95% complete is divided by the total number of variables in the database.

- Level 1: Unknown or few (<50%)
- Level 2: Many (50-79%)
- Level 3: Most (80-97%)
- Level 4: All or almost all (>97%)

Rationale:

If large amounts of data are missing for a particular variable, it becomes difficult to perform any analyses with that variable as any individuals with missing data are excluded from the analysis. This means that selection bias may be introduced into the sample as those with missing data may be systematically different from individuals without missing data.

8.4.1. When was completeness last determined

Definition:

The date (month and year) when completeness was most recently determined.

Rationale:

Shows how up-to-date the assessment is, and therefore whether completeness could have improved or declined since the assessment was conducted.

Date (month and year) when completeness was last determined

8.5. Form in which continuous data (excluding dates) is collected

Definition:

The percentage of continuous variables collected as raw data (the number of continuous variables collected as raw data divided by the total number of continuous variables). A continuous variable is one where the information is on a continuous scale, for example height in cm or blood loss in ml. The data are defined as being collected as raw if no information has been lost in its recording. For example, height should be recorded in cm, not in categories such as 'less than 150cm' or 'greater than 150cm'.

- Level 1: Unknown or few (<70%)
- Level 2: Many (70-89%)
- Level 3: Most (90-97%)
- Level 4: All or almost all (>97%)

Rationale:

Collecting continuous variables as raw data ensures that no information is lost in the recording of that data, enabling the analyses to use all of the available data.

8.6. Use of explicit definitions for variables

Definition:

The percentage of variables which have clear definitions laid out in a document such as a data manual. This is calculated by dividing the number of variables in the database which have been clearly defined by the total number of variables which need to have definitions. Some variables, such as sex and Medicare number, do not need to be defined as their meaning is generally accepted. Such variables are excluded from this assessment.

A definition is a clear description of what the variable means, for example diabetes could be defined as a 'fasting blood sugar over 105 mg %'.

- Level 1: None
- Level 2: Some (<50%)
- Level 3: Most (50-97%)
- Level 4: All or almost all (>97%)

Rationale:

Having clear definitions ensures that everyone collecting the data does so in the same way, producing more reliable data. Thus all individuals recorded as being diabetic will be classified in the same way, allowing meaningful comparisons to be made.

8.7. Use of explicit rules for deciding how variables are recorded

Definition:

The percentage of variables which have clear rules on how to code them in the database laid out in a document such as a data manual. This is calculated by dividing the number of

variables in the database which have clear rules by the total number of variables which need to have rules.

For example, if blood pressure is measured twice, is there a rule determining which reading should be recorded, or if a patient has two addresses, is there a rule to determine which one is reported in the database?

- Level 1: None
- Level 2: Some (<50%)
- Level 3: Most (50-97%)
- Level 4: All or almost all (>97%)

Rationale:

It is important that variables are recorded in the database in the same way to ensure that the data are reliable and that meaningful comparisons can be made between individuals.

8.8. Reliability of coding of conditions and interventions

Definition:

How standardised is the coding for conditions and interventions? For example, does the same person record the same information in different ways (intra-rater reliability), and do different people record the same information in different ways (inter-rater reliability).

This can be tested in a number of ways, for example by conducting a coding audit where different coders are given the same information to code and their coding is compared for concordance (inter-rater reliability). The same person can also be asked to code the same information at different points in time (intra-rater reliability). These tests produce Kappa scores, a measure of concordance where a score of 1 equals 100% concordance, and 0 equals no concordance.

- Level 1: Not tested.
 - No inter or intra-rater reliability tests conducted.
- Level 2: Poor.
 - Low inter and intra-rater reliability (i.e. Kappa <0.5).
- Level 3: Fair.
 - Fair inter and intra-rater reliability (i.e. Kappa 0.5 - 0.8).
- Level 4: Good.
 - Good inter and intra-rater reliability (i.e. Kappa >0.8).

Rationale:

Good inter and intra-rater reliability shows that the data are being consistently recorded and thus that they are reliable. Particular emphasis is placed on reliably recording conditions and interventions, as it is important that any differences in peoples' diagnosis or treatment are due to real factors, and not because the variables were recorded in different ways for different people.

8.8.1. How and when last tested

Definition:

The method by which the reproducibility was tested (e.g. by an external coding audit), and the date (month and year) when this was most recently done.

Rationale:

It is important to know the method used to assess inter and intra-rater reliability to ensure that the method, and therefore the results, are valid. The date when such tests were conducted is also important to ensure that these results are up-to-date.

Methods of determination of completeness of recruitment

Date at which this was last performed?

Notes:

8.9. *Independence of observations of primary outcome*

8.9.1. What is the primary outcome the database is interested in exploring?

Definition:

The principal outcome that the database is interested in exploring. This will vary by condition and according to the purpose of the database. The primary outcome for a cancer database may be remission or death, while one a database on hip prostheses may have loosening of the prosthesis and repeat surgery as their primary outcome.

Rationale:

Only biases associated with the recording of the primary outcome are assessed, as this is the most important outcome as defined by the database, and therefore the one it has most interest in capturing.

Response/notes:

8.9.2. Is there are bias associated with the outcome due to the way in which it was reported?

Definition:

Is there any bias associated with the outcome due to the way in which it was reported?

Level 1: Outcomes not included.

Level 2: Observer neither independent nor blinded to the intervention.

- For example, the treating clinician determines how successful the known intervention was.

- Level 3: Independent observer not blinded to the intervention.
 - For example, the patient, a non-treating clinician, or a data collector assesses the outcome of the known intervention.
- Level 4: Independent observer blinded to the intervention, or not necessary as objective outcome (e.g. death, cancer remission or a lab test).
 - For example an independent clinician or data collector assesses the outcome without knowing what intervention has been conducted.

Objective outcomes include death, cancer remission and lab tests as no bias can be introduced to the reporting of the outcome.

Rationale:

It is possible for those collecting data to introduce bias by mis-reporting the outcome of an intervention if they have a vested interest in doing so. An observer who does not know what the original intervention was (blinded), or who has no vested interest in the results (independent), is less likely to introduce bias. Alternatively, if the outcome is objective, such as whether or not a patient died, or the results of a lab test, then the data are unlikely to be biased.

8.10. Extent to which data are validated

Definition:

What measures are taken to ensure that the data are valid (reflect something real)?

- Level 1: No audit.
 - No data validation is conducted.
- Level 2: Range **or** consistency checks.
 - Range checks ensure that data outside of the permitted range are not allowed, for example an age of 150. Range checks may be pre-programmed into data entry programmes and performed automatically at data entry, or performed manually at the data analysis stage.
 - Consistency checks can be performed manually or automatically, and involve highlighting areas where the data are inconsistent. For example, a consistency check would ensure that an individual having a hysterectomy could not be recorded as male.
 - Some databases may go back to the original records to validate the data by retrieving the correct value, for example by sending back a list of queries to those who collect the data.
- Level 3: Range **and** consistency checks.
- Level 4: Range and consistency checks plus external validation using an alternative source.
 - External validation involves going back to the original record and comparing the information with that held by the database to ensure that the database records are accurate. This would normally take the form of an audit whereby, for instance, a 1% sample of all database records is compared to the original medical notes.
 - Going back to the records to check inconsistencies or range checks by setting up a series of queries does not constitute external validation.

Rationale:

If the data are not valid, misleading results will be obtained.

8.10.1. How last determined

Definition:

The method by which the validity of the data was tested (e.g. by an external audit or by automated range and consistency checks), and the date (month and year) when it was most recently done.

Rationale:

It is important to know the methods by which data are validated, and how regularly it is done, in order to assess whether the data validation is adequate.

Date at which validity was last performed

9. Classification

Each database is classified on five different categories according to what information is collected. For each category between 0 and all of the options can be selected.

9.1. Classification – body system

- Cardiovascular: heart; cardiac; coronary; peripheral vascular; arteries; veins
- Ear, nose and throat
- Gastrointestinal: oesophagus; stomach; intestine; colon; rectum; liver; pancreas
- Haematological: blood
- Mental: psychological
- Metabolic: endocrine
- Musculoskeletal: bones; muscles; tendons
- Neurological: nervous system; brain; spinal cord
- Ophthalmological: eye
- Pulmonary: lung; respiratory
- Reproductive: uterus; breasts; testicles
- Skin
- Urological: kidneys; renal; bladder

Rationale:

This information is used by the search system.

9.2. Classification – pathogenesis (underlying disease process)

- Allergy
- Cancer: malignancy; neoplasms
- Congenital/genetic
- Degenerative: atherosclerosis; aging
- Infections
- Injury: fractures; trauma

9.3. Classification – intervention

- Intensive care: coronary care; dialysis; critical care
- Medicines: drugs; chemotherapy
- Obstetrics: childbirth; maternity
- Primary care: general practice; family practice
- Psychiatric/psychological: psychotherapy; counselling
- Radiotherapy
- Rehabilitation: non-invasive therapies
- Surgery
- Children: usually up to 16 years of age
- Adults: usually 16-64 or working age
- Older people: usually 65+ or retired

9.4. Classification – country

The area from where the database collects information.

- Victoria
- New South Wales
- South Australia
- Western Australia
- Queensland
- Northern Territory
- Australian Capital Territory
- Tasmania
- New Zealand
- Other

9.5. Other potential data sources

We are collecting information on all registries in Australia which contain health-related data. To make sure that we have covered them all, would you know of other existing registries?

Response/notes: _____

Appendix B

Registry of Registries
Example letters to database custodians



Department of Epidemiology & Preventive Medicine

Within the School of Applied Clinical and Public Health Sciences
and the Central and Eastern Clinical School
Faculty of Medicine, Nursing and Health Sciences

[Database custodian]

Thursday, 18 January 2007

Dear [Database custodian]

Re: NHMRC Centre of Research Excellence in Patient Safety Registry of Registries

Over the past four months the NHMRC Centre of Research Excellence in Patient Safety has collected information from registry custodians about the attributes of the registries currently in existence in Australia. You were asked to provide details on the [Registry title]. The purpose of this survey was to develop a registry of registries.

There were three requirements to be eligible for inclusion in this registry:

- (a) collect patient or clinician-specific data continuously;
- (b) collect outcome data as a function within the registry, and not primarily through linkage with outcome databases such as the Registry of Births, Deaths and Marriages or the National Death Index;
- (c) collect information pertaining to more than one healthcare institution.

This information has been collated. Attached to this letter are details of the [Registry title] as provided by you or your delegate. We ask that you check for completeness and accuracy of the data.

We intend to make this information available to the Australian Commission for Safety and Quality in Health Care in the format of a report. We will also forward to you the completed report for your perusal. The Commission may wish to use this report to assist in identifying where potential investment might be made in developing registries nationally.

I await your feedback.

Yours sincerely,

Professor Peter Cameron
A/Director, NHMRC Centre of Research Excellence in Patient Safety
Department of Epidemiology and Preventive Medicine
Alfred Hospital Campus,
Monash University