

Australian Clinical Quality Registries Project for ACS&QHC

Final Report

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Centre for Health Service Development



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Frances Simmonds

Lauren Jones

Monique Berger

Jodie Tazelaar-Molinia

Ming Zhang

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Introduction

The Australasian Rehabilitation Outcomes Centre (AROC) is a clinical registry that provides a national benchmarking system to improve clinical rehabilitation outcomes. The registry is a sub-centre within the Centre for Health Service Development (CHSD), University of Wollongong (UoW) under which it is governed. Membership of AROC covers the vast majority of rehabilitation units (public and private) in Australia.

AROC is a pilot site for the testing and validation of the draft Operating Principles and Technical Standards developed by Australian Commission on Safety and Quality in HealthCare (the Commission) which is Phase 3A of the Commission's broader undertaking called 'The Australian Clinical Quality Registries Project'. Phase 1 and 2 of the project involved the standards development, technical and data design. After this testing and validation phase during Phase 3A, an evaluation process will take place (Phase 3B) followed by national recommendations (Phase 4) for Australian registries.

Assessing AROC against the Operating Principles and Technical Standards will allow AROC to benchmark itself in a way not available previously. This assessment will then inform AROCs development in the future, allowing AROC to participate in the coordination and linkage of registry information in Australia.

For the pilot project (Phase 3A), AROC has identified 10 activities as key milestones:

1. Activate project
2. Consultation with key stakeholders
3. Assessment of AROC against Operating Principles & Technical Standards & Development of Action Plan
4. Liaison with other Pilot Sites
5. Development of AROC Data Dictionary
6. Development of AROC Quality Assurance Plan
7. AROC Dataset/ Data Collection Training
8. Formalise AROC Data Policies
9. Undertake Required Interim Reporting
10. Prepare Final Report

This is the final report of this project.

1. Assessment of AROC Against Operating Principles and Technical Standards

The actual assessment of the AROC registry was undertaken against the document called “*Draft Operating Principle and Technical Standards for Australian Clinical Quality Registries*” developed by the Commission in collaboration with the NHMRC Centre for Research Excellence in Patient Safety (CRE PS) at Monash University and the National E-Health Transition Authority (NEHTA). As a national registry, AROC is well positioned to inform the draft standards, identify any issues or barriers relating to the draft standards and to provide recommendations which will maximise benefit and knowledge for quality Australian registries.

Results of the assessment are set out in this report in 4 main sections:

1. Background and scope of the AROC data collection.
2. Method for assessing AROC against the operating principles & technical standards.
3. Evaluation of AROC against the operating principles for Australian Clinical Quality Registries including timeframe for implementing changes.
4. Evaluation of AROC against the technical standards (architecture and standards map).

2. Background and Scope of AROC Data Collection

AROC is an existing national registry which gathers and analyses clinical information with the objective of improving outcomes in rehabilitation. It was established by the rehabilitation sector in 2002, with membership covering the vast majority of rehabilitation units, public and private. AROC is a joint initiative of the Australian rehabilitation sector (providers, payers, regulators and consumers).

AROC is somewhat unique as a clinical registry as it collects de-identified episode level information. The data provided belong to a rehabilitation facility which is the member of AROC. AROC does not have a relationship with any rehabilitation patient. This is important as this structure impacts the relevance of some of the Operating Principles and/or AROC’s ability to comply with some of the Operating Principles.

The Australasian Faculty of Rehabilitation Medicine (AFRM) is the auspice body and data custodian. The Centre for Health Service Development (CHSD) is the data manager and responsible for the day to day operations of AROC. AROC is currently funded on an annual basis by contributions from all stakeholders, private rehabilitation units, state departments of health (on behalf of the public rehabilitation units in their state), health funds, Commonwealth Department of Health & Ageing, Department of Veterans’ Affairs, AFRM and various general insurers.

A rehabilitation medicine service aims to provide people with loss of function or ability due to injury or disease with the highest possible level of independence (physically, psychologically, socially and economically). This is achieved through a combined and co-ordinated use of medical, nursing and allied health professional skills. Rehabilitation involves individual assessment, treatment, regular review, discharge planning, community integration and follow up of people referred to that service. The provision of a national benchmarking system to improve clinical rehabilitation outcomes, which is the role of AROC directly supports the rehabilitation process (i.e. to maximise a person’s abilities and independence, restore lost

function, prevent new or further functional loss and work with other health care professionals).

The AROC registry is episode based (i.e. each rehabilitation inpatient episode is reported by member providers) and information is reported on each rehabilitation occasion. Episodes for the same individual are not matched within the database to form patient level information. AROC coverage is estimated at 98% of all rehabilitation occasions of inpatient services and the registry reports biannually on functional index measures for people receiving such services. The registry maintains six years of data (from 2002 through to present) and AROC plans to extend the collection to non inpatient services (ambulatory rehabilitation) and paediatric services (both inpatient and ambulatory).

This report concentrates on describing the process relating to inpatient data collection, as this process is relatively mature, whilst the ambulatory data collection is just beginning.

The Functional Independence Measure (FIM) is the primary rehabilitation outcome measurement contained in the AROC inpatient dataset. AROC holds the territory license for the use of the FIM (and WeeFIM) in Australia, and is the national certification and training centre for these tools. The FIM is used to measure functional change and the burden of care at discharge for each individual. Studies have found the psychometric properties of the FIM instrument to be reliable and valid, with good predictive validity of FIM scores by outcome variables such as length of stay.

Each of the 18 items within the FIM Instrument is assessed against a seven point ordinal scale, where the higher the score for an item, the more independently the patient is able to perform the tasks assessed by that item. Total scores range from 18 to 126. The items are divided into two major groups - 13 Motor and 5 Cognitive Items. The rating scale designates major graduations in behaviour from dependence to independence. The scale provides for the classification of individuals by their ability to carry out an activity independently, versus their need for assistance from another person or a device. If help is needed the scale assesses the degree of that help. FIM data can be reported in terms of FIM Motor scores (the sum of the 13 FIM motor items), FIM Cognitive scores (the sum of the 5 FIM cognitive items), or FIM Total (the sum of all 18 FIM items).

3. Method for assessing AROC against the Operating Principles and Technical Standards

The main aims of assessing AROC against the Operating Principles and Technical Standards are to:

- inform the development of Australian Clinical Quality Registry standards through the application of the draft Operating Principles and Technical Standards against an existing national registry or to the development of a new registry;
- conduct a detailed assessment of the relevance, ease, cost and likely timeframe of implementing new standards if seen as desirable and identify any issues or barriers relating to the draft standards which would limit uptake by registries; and to
- provide recommendations which will maximise benefit and knowledge gained, thus promoting best practise and optimal information for Government and other key stakeholders to make decisions on the final principles and standards to be adopted.

A timeframe for implementing those operating principles that AROC believes are appropriate and as yet do not comply with, will be a by product of this work.

The assessment process was achieved as follows:

Step 1 An initial assessment of AROC against the draft Operating Principles and Technical Standards was undertaken as part of the submission process, including the determination of the AROC 'registry type' for the assessment process.

Step 2 A detailed assessment which included an additional assessment of the relevance, ease and cost and likely timeframe of implementation if implementation is seen as desirable, commenced on announcement of success of tender in mid October. The draft Operating Principles and Technical Standards document (provided as part of the tender documentation) was used until the final version was provided to AROC on 20 November 2008.

This process included evaluation of the criteria under the two primary assessment components outlined in the Commissions documentation:

- operating principles; and
- technical standards (including architecture overview and standards map).

Step 3 For the assessment of the Technical Standards, NEHTA, ISO, XML and the TOGAF standards referenced in the *"Draft Operating Principle and Technical Standards for Australian Clinical Quality Registries"* were reviewed.

Step 4 Initially, standards relevant to a Level 2 registry were evaluated in order to contain scope (see comment below). The review was later expanded to standards that may be relevant to future uptake by AROC.

Step 5 Where necessary, additional information has been sourced from NEHTA, ISO and IT experts at the University of Wollongong. The study team were familiar with SNOMED CT having conducted studies that included the need for review of SNOMED CT architecture and content which benefited the assessment process.

The initial assessment of AROC against these Operating Principles and Technical Standards indicates that AROC follows wholly, or in part, many of the standards. As pointed out in the document provided by ACSQHC called 'Learnings from Alpha Testing the Standards, the technical standards referred to in the 'Standards Map' are numerous with some referencing other multiple standards. The time, resources and technical expertise required to conduct a comprehensive review of these standards and their potential applicability to AROC is significant. In addition whilst some standards are available in the public domain others must be purchased. For these reasons, we initially targeted those technical standards relevant to a Level 2 registry along with standards that would address fundamental structural and process issues that require attention in order for the quality of the data being contributed to the registry to be enhanced.

4. Evaluation of AROC and operating principles for Australian Clinical Quality Registries

The Commission's document for Australian Clinical Quality Registries sets out 42 operating principles that should ideally be followed by Australian clinical registries. In this section, we have firstly summarised AROC operational policies (see Table 1) against each of the principles listed and identified whether AROC:

- complies with the principle;
- partially complies with the principle;
- plans to comply in future and timeframe for implementation; or
- does not plan to comply.

The sections that follow Table 1 detail how AROC operates in relation to each principle. Where AROC does not fully follow the principle or intends to follow the principle in the future, steps/actions to achieve the principle are provided.

Although the operating principles reviewed here are linked to many of the technical standards examined in the next section, the principles relate directly to AROCs organisational policy and operating procedures and have therefore been discussed and presented separately in this report.

Understandably, there was some overlap with the content of the principles evaluated under some of the sections. Where this occurred, we have provided cross references.

Table 1 Evaluation of AROC with operational principles

Operating Principles	AROC compliance with principle			
	Comply	Partially comply	Plan to comply in future & timeframe	Do not plan to comply
Attributes of clinical registries				
1	Collect data with clear & defined purpose			
2	Contains a core minimum data-set			
3	Collect epidemiologically sound data elements			
4	Uniformly collect data – i.e. Level 2 ⁽¹⁾		Req dev health IT infrastructure	
5	Outcome measure taken at time of clinical stabilisation			
6	Burden of cost/data collection against loss to follow-up			
7	Data collected from eligible population			
Data collection				
8	Data capture enhances health care and not a burden		AROC IT Upgrade Project commenced	Next 6 months
9	Data capture is done close to time of care			
10	Uniformly collect data & easily accessible			
11	Standard definitions, specifications used to collect data		No progress	Ongoing
12	Data dictionary is established			
13	Existing data sources are utilised for data collection		Progress some jurisdictions	Ongoing
14	Record linkage is available			On SCAC agenda
Data elements				
15	Identifying information is collected			
16	Process of care measures are collected			
17	Outcome measures assessed with objective measures			
Risk adjustment				
18	Collect objective reliable covariates for risk adjustment			
Data security				
19	Secure access, transfer and messaging		AROC IT Upgrade Project	Next 6 months
20	Secure data storage			
21	Authentication & institutional policies followed		AROC IT Upgrade Project	

Operating Principles	AROC compliance with principle			
	Comply	Partially comply	Plan to comply in future & timeframe	Do not plan to comply
Ensuring data quality				
22	Ascertainment - percentage of eligible patients			
23	Robust quality control plan			
24	Data checked in a sample of cases			
25	Built in data management processes			
26	Reports provided in strict timeline and funded			
Organisation and governance				
27	Accountable formalised governance			
28	Manage contingencies from data analysis with policy		SCAC Agenda next 6 months	
Data custodianship				
29	Data custodianship must be explicit			
30	Access & reporting policies are available			
31	Third party access approved by Steering Committee			
Ethics and privacy				
32	IEC must be obtained to establish registry			
33	Personnel must be familiar with ethical conduct			
34	Participants must be informed about data use			
35	IEC approval must be sought for projects			
Information output				
36	Data used for best practice/benchmarking performance			
37	Reporting on risk adjustment outcome analysis			
38	Verify data collected through peer review			
39	Ad hoc data analysis to monitor clinical findings		AROC IT Upgrade Project	6 Months
40	Annual reporting			
41	Documented procedures for outlier reporting		SCAC Agenda next 6 months	
Resources and funds				
42	Resources and funds			

1 AROC data are uploaded using a one way web-based submission process – which is described as a Level 2 data registry in the Technical Standards and Architecture Overview (pg 72).

4.1 *Attributes of Australian Clinical Quality Registries*

Principle 1 Australian Clinical Quality Registries should be developed with clear and precisely defined purposes

Assessment: Relevant – AROC complies.

AROC continually measures performance and operational outcomes in line with the registry purpose. The purpose and aims of AROC was clearly defined at inception and have not been altered since. The aims of AROC are to:

- Develop a national benchmarking system to improve clinical rehabilitation outcomes in both the public and private sectors.
- Produce information on the efficacy of interventions through the systematic collection of outcomes information in both the inpatient and ambulatory settings.
- Develop clinical and management information reports based on functional outcomes, impairment groupings and other relevant variables that meet the needs of providers, payers, consumers, the States/Commonwealth and other stakeholders in both the public and private rehabilitation sectors.
- Provide comparative data to subscribers using national and international benchmarks.
- Provide and coordinate ongoing education, training and certification in the use of the FIM and other outcome measures.
- Provide annual reports that summarise the Australian data.
- Develop research proposals to refine the selected outcome measures over time.

Principle 2 For Australian Clinical Quality Registries to provide the maximum value to the health system they should focus their core data collection on the essential elements required to serve their main purposes

Assessment: Relevant – AROC complies.

AROC grew out of the establishment of AN-SNAP, the casemix classification system for the sub-acute sector. The Australasian Faculty of Rehabilitation Medicine (AFRM) facilitated the development of AROC and remains the data custodian. The rehabilitation clinicians wanted to be able to use AROC to capture information about the care they provided, and compare their outcomes with outcomes of their peers.

AROC commenced operations in July 2002, with the prime objective being the collection of a standardised dataset against each and every rehabilitation episode of care. Data represent the patient episode, and the essential elements (the AROC 'data items') were originally based on the UDSmr dataset and revised by the AROC Scientific and Clinical Advisory Committee (SCAC) for the purpose of the collection. AROC Version 3.0 is the latest inpatient dataset and Version 1.0 for ambulatory dataset.

Collection of rehabilitation episode data has enabled the provision of a national benchmarking system, which in turn has led to an improved understanding of factors that influence rehabilitation outcomes and costs, and therefore performance of the sector.

The core data collection is regularly reviewed by the AROC SCAC to ensure the collection serves the rehabilitation sector in providing benchmark information.

Future plans include the identification and collection of additional impairment specific datasets that will provide more specific outcome information for each particular impairment type. In addition, in order to address specific issues, it is likely additional data items may be collected from time to time on a time limited basis.

Principle 3 Data collected by Australian Clinical Quality Registries should be confined to items which are epidemiologically sound, i.e. simple, objective, and reproducible

Assessment: Relevant – AROC complies.

Copies of the current AROC datasets can be found at <http://chsd.uow.edu.au/aroc/>. AROC datasets contain primarily de-identifiable patient information for each rehabilitation episode and have been developed using data definitions where they are available. The dataset includes demographic, funding, episode, clinical, and outcome items. Of the 42 data items in the inpatient dataset, 15 currently meet Australian standards definitions as defined in Australian standards documents.

AROC have been working with the National Data Development and Standards Unit, AIHW for more than 5 years in order to achieve inclusion of the AROC inpatient dataset in the National Health Data Dictionary (NHDD). Review of the AROC inpatient dataset continues to be an item on the workplan of the recently established National Health Information Standards and Statistics Committee (NHSSC). The barrier to acceptance has been that rehabilitation is a type of sub acute care, and to date much of the national standards work around minimum datasets has been around acute care. AROC has found that the structure of sub acute care does not necessarily fit tidily within an acute care structure. This has resulted in significant difficulty in getting the AROC data set accepted into the NHDD, even though this dataset is currently collected by the overwhelming majority of rehabilitation units in Australia.

Principle 4 Methods used to collect data in Australian Clinical Quality Registries should be systematic, with identical approaches used at the different institutions contributing information.

Assessment: Relevant – AROC partially complies.

Data against the AROC dataset are recorded at facility level largely using paper forms. Most facilities use either their PMS or the SNAPShot database software to capture these data from the paper forms. Data are subsequently submitted to AROC via web upload quarterly.

The IT Upgrade currently being undertaken by AROC will replace SNAPshot with a (optional to use) web based front end for data collection. This will improve the data collection process for those facilities who use it, but achieving absolutely identical data collection processes at all member institutions is not likely in either the short or long term.

AROC acknowledges that the manual collection of data is a major limitation, however, at this stage of the development of the IT infrastructure underpinning health, it is not possible to automate this process. For details refer to Principle 8.

Principle 5 Outcome determination should be undertaken at a time when the clinical condition has stabilised and the outcome can therefore be reasonably ascertained.

Assessment: Relevant – AROC complies.

The AROC collection maintains high compliance for outcome assessment because the FIM assessment tool is endorsed by the AFRM, functional assessment is fundamental to rehabilitation and because timely assessment of function is a clinical indicator. In addition, AROC provide training, workshops and regular communication regarding FIM and AROC dataset collection with facilities.

The outcome measure for AROC is assessed using the FIM instrument at admission and discharge. Admission data are required to be collected within 72 hours of admission, and discharge data within the 72 hours prior to discharge. Assessment is undertaken by direct observation by clinicians familiar with the patient's daily activities, and is often a multidisciplinary process. The score should reflect the actual performance observed.

As the patient's functional ability may change from day to day the timing of the FIM assessment at admission and at discharge is important. To measure the timeliness of FIM scoring on admission and discharge, the AROC data set requires the collection of the date on which each of these scores was collected. It should also be noted that timeliness of functional assessment is an Australian Council on Healthcare Standards (ACHS) Rehabilitation Medicine clinical indicator.

Principle 6 In determining the time to outcome assessment, Australian Clinical Quality Registries must consider the burden and cost of data collection together with the likelihood of loss to follow-up.

Assessment: Relevant – AROC complies.

AROC liaises closely with member providers to ensure minimum burden and reduction in missing data.

The AROC team support the collection through training programs, provision of revised data items and provision of proforma data collection forms to ensure minimal burden on facilities. Because the data are episode based and provided against each occasion of service, loss to follow-up is negligible. Nonetheless, there is a potential for missing data which facilities monitor using the audit and benchmark reports provided to them by AROC.

Principle 7 Australian Clinical Quality Registries must ensure that complete registry data are collected from the eligible population

Assessment: Relevant – AROC complies.

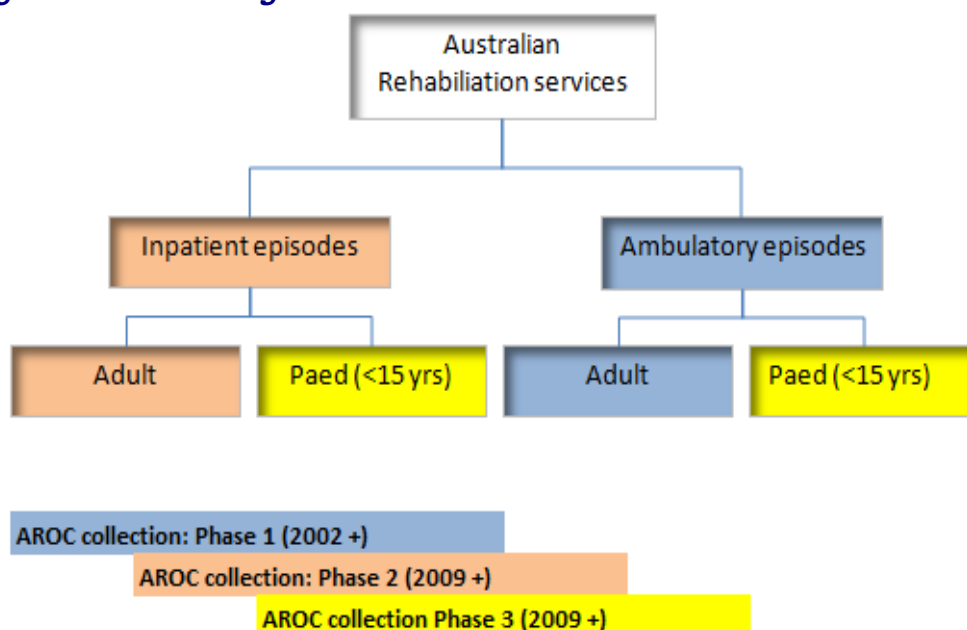
AROC membership currently covers 95% of all rehabilitation inpatient beds (public and private) in Australia, with 155 of the estimated 165 rehabilitation units in Australia submitting data covering more than 60,000 episodes each year. The recruitment of New Zealand inpatient facilities has begun, with 18 units currently members and commitment to join from up to 6 more.

From 2009, the registry will begin to contain data representing ambulatory rehabilitation episodes in Australia.

In total, the AROC database now comprises data describing more than 400,000 episodes of inpatient care. Figure 1 illustrates the AROC coverage now and for the future.

It is clear to each member upon recruitment to AROC that membership requires a commitment to collect data against each and every episode of rehabilitation they provide. For each unit, AROC reports the number of episodes received each month as part of the bi-annual benchmarking reports. This highlights any data anomalies, such as missing episodes to the facility.

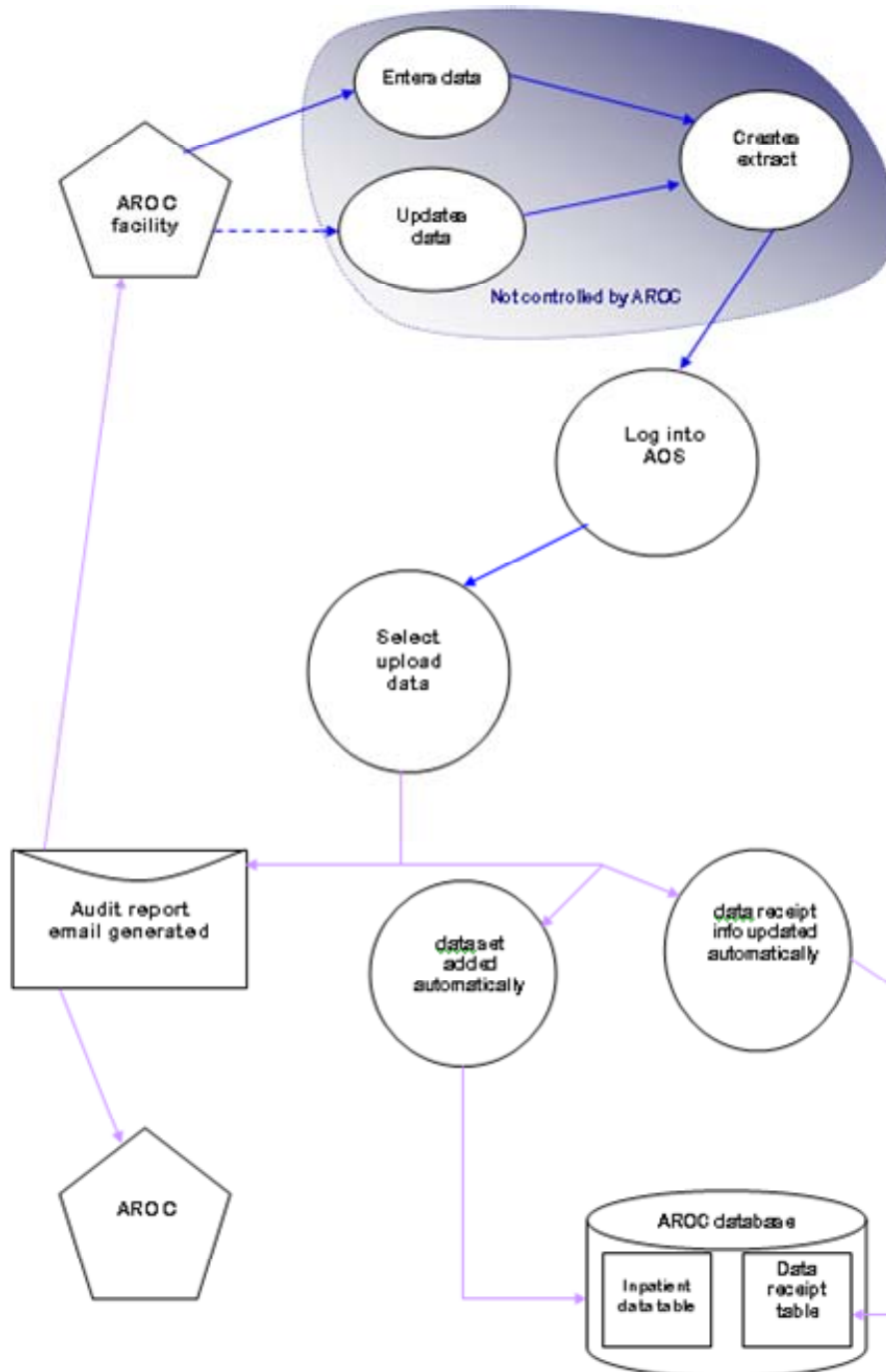
Figure 1 Coverage of the AROC data collection



4.2 Data Collection

AROC receives two different data sets, the inpatient data set (collected since the inception of AROC in 2002) and the ambulatory data set (commenced January 2009). AROC members choose how they wish to collect the AROC data sets. Many use the software SNAPshot, some jurisdictions have built the AROC dataset into their PAS, some use add-ons to their PAS, while others merge several data sources. Figure 2 shows the future data flow of the AROC collection.

Figure 2 Future data flow of the AROC collection



AROC are currently reviewing the data flow procedures for upload of data as part of their IT & IM enhancements. The key difference between data receipt of inpatient data today and in the future is the automation of the two steps – the addition of the data into the inpatient data table and the recording of data receipt information.

A primary goal of the enhancements is to combine the many databases held at AROC into one relational database accessible via the new AROC Online Services. The intention is to minimise errors in member data by allowing additions and updates to only have to be done once.

The new AROC Online Services will be an online portal to full AROC functionality, enabling access to all AROC members and staff from anywhere anytime.

Principle 8 The collection of data for an Australian Clinical Quality Registry must not impact on the provision of health care and should not be a burden or incur a cost to consumers

Assessment: Relevant – AROC partially complies.

Action: Within the context of providing a practical process, AROC does aim to have as many facilities as possible fully automating the data collection process without burden or additional cost to member providers. This will be achieved by continual encouragement of jurisdictions to build the AROC dataset into their PMS, and where that is not possible, through the enhancement of AROC's system. The estimated cost of the AROC IT enhancements is \$400K.

At this stage the IT infrastructure underpinning health is not developed sufficiently to allow all facilities to utilities a fully automated system. Consequently, the current data collection process at AROC is a hybrid of paper based and electronic data capture.

Forty two standard data items are collected for each inpatient episode. AROC provide members with a proforma form for data collection which is generally used to collect the data items during the patient episode. The AROC data items are clearly aligned with the process of providing rehabilitation and are items of information that the providers collect anyway as part of the provision of care.

Data are then captured at the facility level using the PAS or the software SNAPshot or add-on software to the facility PAS. Data are subsequently uploaded via the Web at a minimum of quarterly intervals. The AROC data collection process is not fully automated at the facility level, however, the paper capture process allows flexibility at facilities (particularly smaller ones). Consequently, resources are used appropriately in line with the patient care model. The automated capture process and upload enables member facilities to take advantage of the audit trail and data check processes.

This Principle is idealistic, but in reality data collection will create a burden, and any burden comes at a cost, and whilst consumer may not incur that cost directly, ultimately the system has to pay, and it is the consumers that fund the system.

Principle 9 Data capture should be performed as close as possible to the time and place of care by appropriately trained data collectors

Assessment: Relevant – AROC complies.

Data for AROC are collected at the point of care and transmitted to AROC on a quarterly basis. Data are however collected onsite during the course of the patients stay. In

particular, the FIM outcome measure for AROC is assessed at admission and discharge. Admission data are required to be collected within 72 hours of admission, and discharge data within the 72 hours prior to discharge. AROC provides reports about data capture performance so that training needs are highlighted. For training, AROC provides regular dataset and FIM training workshops and are in regular communication with facilities about data capture.

Principle 10 Data should be uniformly and easily accessible from the primary data source

Assessment: Relevant – AROC complies.

In AROC's case the primary data source is each of the facilities that are members. AROC has a standard data file naming convention against which all facilities provide data extracts. These extracts are uploaded across the Web to AROC using AROC Online Services (AOS). AROC Online Services (AOS) is a web based reporting system that automates the processes of data submission, auditing and reporting for AROC member rehabilitation facilities across Australia.

In order to submit data to AROC, member facilities must follow a strict data format with a naming convention that identifies the data set, version and if SNAPshot used.

Security measures for data transfer, authentication, housing and messaging are detailed in Section 3.5.

Principle 11 Standard definitions, terminology and specifications should be used in Australian Clinical Quality Registries wherever possible to enable meaningful comparisons to be made and allow maximum benefit to be gained from linkage to other registries and other databases (if approved by relevant ethics committees)

Assessment: Relevant – AROC partially complies.

Action: As resources allow, AROC will continue to work with DOHA and the AIHW to have the AROC domain specific data items included in the national minimum datasets or as subsets to them. The potential for AROC to adopt a subset of SNOMED CT concepts or consider developing AROC as an extension terminology will require formal evaluation as a SNOMED CT license holder.

Barriers: Rehabilitation is a type of sub acute care. To date much of the national standards work around minimum datasets has been around acute care. AROC has found that the structure of sub acute care does not necessarily fit tidily within an acute care structure. This has resulted in significant difficulty in getting the AROC data set accepted into the NHDD, even though this dataset is currently collected by the overwhelming majority of rehabilitation units in Australia.

The AROC data sets contain standard classification tools for measuring functional capacity, national standards for demographic data and specific values for items not yet developed as a national standard or classification.

The first of the classification tools, used in the inpatient dataset, is the Functional Independence Measure (FIM) which is the primary inpatient rehabilitation outcome measurement. The FIM is a global scaling system used to measure functional change and the burden of care at discharge for each individual. The parameters of the FIM are described in Section 2 of this report.

The FIM is used in conjunction with the AROC Impairment Codes which are based on UDSmr Impairment Codes, adjusted for Australian clinical conditions. The impairment codes are broad groupings based on one or many different diagnostic etiologies. Understanding the underlying cause of dysfunction is important clinically as well as for correlating with improvement of function recorded by FIM. These Impairment Codes can be accessed through the AROC website <http://chsd.uow.edu.au/aroc/>. Guidelines for the application of the impairment codes are available on the AROC website to assist members with accurate assessment. The impairment groups do not intend to capture each underlying diagnosis, however, there is potential to map to the impairment codes from other classifications and terminologies such as ICD-10-AM or SNOMED CT. Such mapping exercises would allow data from other registries to be potentially linked to AROC.

AROC contains several of the Australian code sets from the National Standards where it has been possible to be compliant. As national standards are still emerging, AROC has been developed without the benefit of these. Where available, the AROC data set incorporates standard code sets and measurements and has the capacity to contribute to development of nationally standardised sets relevant to the rehabilitation domain. Other remaining data items in the AROC data set have terms and concepts specific to the AROC collection. Over the past 5 years AROC has been working with DOHA and the AIHW to have several of these rehabilitation specific data items included in National Minimum Datasets.

There is potential for AROC to utilise a subset of concepts held in the SNOMED CT terminology as data values. Initial comparison of the AROC concepts with SNOMED-CT show reasonable comparability, however, care will need to be taken to ensure that when AROC is compared and contrasted to SNOMED-CT that the model which defines the hierarchies and relationships in SNOMED CT are considered. To be thorough, a feasibility study would best address the value of using SNOMED-CT and its semantic interoperability with AROC. Comparing at the concept level only, can lead to incorrect conclusions about logic and content.

Principle 12 Australian Clinical Quality Registries must use data dictionaries when they are established to ensure that a systematic and identical approach is taken to data collection and data entry. They need to publish eligibility criteria, metadata, data dictionaries, etc.

Assessment: Relevant – AROC complies.

As part of this project AROC has expanding its data dictionary. The process relating to that development is outlined in Section 6 of this report.

Previously AROC maintained a catalogue called the AROC Inpatient Clinical Data Set which contained of all the data items held in the database and information about them. AROC data items promote uniform consistent and complete data through the use of standardising values – there are no free text items (except an optional comments section). Wherever possible, AROC utilises national standards and classification tools for the data collection as outlined under principle 11. The Clinical Data set and training in its application is provided to AROC member facilities.

Principle 13 To avoid duplicating data capture, Australian Clinical Quality Registries use data from existing data sources, including administrative data, where they are of a satisfactory quality

Assessment: Relevant – AROC partially complies.

Action: AROC will continue to work with members on short and long term plans to address the issue of duplication of effort.

The principle of utilising existing data sources to capture part or all of a clinical registries dataset is sound. In practice however, this is difficult to achieve. As the Operating Principles point out, the variability in hospital information technology systems and coding practices and the lack of recording of essential clinical data make the accessibility and utilisation of data from existing data sources troublesome.

The uniqueness of the AROC database means that these data are often not available in existing administrative and clinical databases, with the exception of the demographic data held. AROC members utilise many different Patient Management Systems, and whilst it is a long term goal, in the short to medium term it is not feasible to write middleware between each of these systems and SNAPshot (or the new AROC IT system once it is developed). Having said that, some jurisdictions place such importance on the collection of the AROC dataset that they have built the dataset into their PMS (some private sector groups), or into their minimum dataset collection tools (Qld Health; NSW Health). The advantage to member units is the avoidance of double data entry. The impact for AROC is that the lead time for the introduction of new dataset versions has to incorporate any necessary lead time for each of these systems.

Principle 14 Australian Clinical Quality Registries should have the capacity to enhance their value through linkage to other disease and procedure registries or other databases.

Assessment: Relevant, but not undertaken to date

AROC recommends the operating principles include the ability for registries to sustain de-identified data sets but enable linkage through a nationally supported UHI.

Action: AROC data are episode based and de-identified, however, the introduction of the UHI will enable the data to be reported as patient level data and linked and shared with other registry data without impacting confidentiality of the information.

Barriers: Modifying ethics may impact on time and cost to AROC unless jurisdictions have existing agreements for healthcare data in the rehabilitation domain to contain the UHI. The need for review of ethics and consent will depend on interpretation of the changes to the Privacy Act for exchange of health information nationally and the timing and nature of agreements in place with each jurisdiction.

Individuals that receive health care trust that the care is received in a system that protects their privacy. Data custodians must operate in a manner that assures these expectations. However, meeting the broader health needs of society, and indeed to ensure that best practice medicine is delivered, requires that information be shared and evaluated for health planning and research. The linkage of information is required to enhance these processes.

In a federated system such as Australia, health data linkage is multifaceted and complex, primarily due to the need to address the concerns, laws and information models of multiple jurisdictions. The development and ongoing expansion of AROC as a national data collection has been achieved within this context. One of the reasons that AROC has high coverage and compliance in the collection of data is that the data are de-identified (that is, the data set excludes specific values that can directly identify a person – see also Principle 13).

AROC intend to maintain a de-identified data set but believe its value will be enhanced through linkage to other disease and procedure registries. This is particularly important as

many of the patients having rehabilitation will have come through the acute system first, and the ability to link registry information across the continuum of care will be important in improving the quality and safety of Australian healthcare.

Data linkage will be a key component of the development of the electronic health record and in the longer term, registry data will become part of the larger repository of information for the EHR. It is envisaged that AROC can retain a de-identified data set if the UHI is available as a re-identified data item from the source provider. Ideally the UHI would be included as an additional data item. University ethics approval and approval from each jurisdiction would be required. Historical data would remain episode based and unmatched.

Whilst AROC does not currently participate in data linkage the subject is on the agenda of the AROC SCAC for consideration.

4.3 Data Elements

Data elements are referred to as (AORC) data items in this report.

Principle 15: Australian Clinical Quality Registries should collect individually identifiable patient or subject information

Assessment: Not Relevant - AROC do not intend to match data within the database to report patient level information or enable linkage of the data with an external database in the short term. See recommendation under Principle 14.

Barriers: State and Federal Privacy laws - see Principle 14.

As stated, AROC contains de-identifiable information. It might be possible to use limited data items in a probabilistic match process and then re-identify for data linkage but it has not been the policy of AROC to use the data in this way. Furthermore, when probabilistically matching data, it is desirable to have identifiable data items such as name, address etc. Whilst AROC does contain some data items that could be used for probabilistic matching, there are insufficient patient identifiable data items to ensure a robust matching process.

Principle 16: Where patterns or processes of care have an established link to outcomes and process measures are simple, reliable and reproducible, they should be considered for collection by Australian Clinical Quality Registries;

Assessment: Relevant – AROC complies.

The AROC data collected contain several process measures including:

- Time since onset or acute exacerbation of chronic condition
- Date episode start FIM assessed
- Date episode end FIM assessed
- Date multi-disciplinary team rehabilitation plan established
- Date discharge plan established

Principle 17: Where possible, outcome should be assessed using objective measures. Where this is not possible, outcome should be assessed by

an independent person and undertaken using standardised and validated tools.

Assessment: Relevant – AROC complies.

The FIM is a globally accepted validated tool for assessing the functional capacity of individuals and is successfully used in the AROC inpatient data collection to monitor and evaluate outcomes associated with rehabilitation treatment. Studies have found the psychometric properties of the FIM instrument to be reliable and valid, with good predictive validity of FIM scores by outcome variables such as length of stay.

The FIM outcome measure for AROC is assessed at admission and discharge by clinicians trained in the scoring system. AROC holds the territory license for the use of the FIM (and WeeFIM) in Australia, and is the national certification and training centre for these tools. Staff using the FIM are required to be trained in the use of the tool and must sit a credentialing exam every two years to ensure consistency of reporting. These processes maximise the quality of the data in the AROC database.

4.4 Risk adjustment

Principle 18: Australian Clinical Quality Registries should collect objective, reliable co-variables for risk adjustment to enable factors outside the control of clinicians to be taken into account by using appropriate statistical adjustments.

Assessment: Relevant – AROC complies.

The AROC dataset contains data items which are used by AROC to risk adjust when undertaking analysis of the data (e.g. age, sex, type of unit, comorbidities). In addition the AROC dataset enables classification of each episode into an AN-SNAP category, allowing casemix adjustment to be undertaken.

4.5 Data security

The data collection process at AROC was outlined in Figure 2 in Section 3.2. Data security practices at AROC are undertaken in accordance with the Privacy Act and principles followed by each jurisdiction (see also Ethics under section 3.9). Further details about the standards followed by AROC are assessed under the technical standards section.

Principle 19: To protect register data, Australian Clinical Quality Registries must utilise secure access controls and secure electronic transfer and electronic messaging systems.

Assessment: Relevant – Currently AROC partially complies. When new IT system operational (end 2009) AROC will fully comply

The following processes are followed at AROC for external access controls, and secure Electronic transfer and messaging from member facilities to AROC.

- AROC data are protected under the University's information data transfer protocol.
- Facilities are provided with a password in order to submit their data and to access their benchmark reports. Reaccess of data already submitted also requires a password.
- Data are transmitted in a flat file ASCII fixed format which adds security because the variable width must be known to convert the file into readable format.
- Although data are submitted using AOS, the uploaded data are currently stored as multiple ASCII files in one of two folders on the AROC server (depending upon the error status of the data). It was originally planned for the AOS database to contain a table that stored the uploaded data and this is included in the IT System enhancements.
- The University has been exploring methods for transfer of data in an encrypted format to ensure the AROC security processes are as up to date as possible.
- When the benchmark reports are downloaded onto the AOS for contributors to access, the system sets up a temporary folder so that access is from the temporary folder and not the UoW server.

The upgraded IT system will utilise state of the art methods for encrypting data supplied by member facilities to prevent against unauthorised data access during transmission.

Principle 20: The collection, storage and transmission of clinical registry data must be in line with relevant legislation and guidelines.

Assessment: Relevant – AROC complies.

All data received by AROC are in electronic format. Storage of the electronic data is on a secure password protected server located in a physically secure computer room of the University of Wollongong. Only members of AROC involved in management and analysis of AROC data have access to these files on the server, with transient storage of working datasets on local password protected desktop computers as required for analysis.

No paper storage of data is required by AROC as the data are received electronically. AROC maintain a durable version control for episode data provided by facilities, identified by the hospital ID, MRN and episode begin date. AROC attaches an ID to each episode for unique identification. Summary data are not reported if the cell size for any single data items is less than five.

Principle 21: The institutional policy principles set out in Part B: Technical standards should be met.

Assessment: Relevant – AROC partially complies.

See section 4.

4.6 Data quality

Principle 22: Australian Clinical Quality Registries should report as a quality measure the percentage of eligible patients recruited to the clinical registry

Assessment: Relevant – AROC complies.

See discussion under Principle 7. AROC is confident that all members provide data against each and every episode of rehabilitation they provide. However, AROC does not, at this stage, cross-check data with any other data source (triangulate). Such a process may be considered at a later date but is not deemed necessary at present.

Principle 23: Australian Clinical Quality Registries should have a robust quality control plan which allows ongoing monitoring of the completeness and accuracy of the data collected

Assessment: Relevant – AROC complies but process could be enhanced.

Action: Activity 6 (reported against at Section 7 of this report) of the current project aims to enhance AROC's quality assurance plan.

AROC seeks to reduce the variability in content and quality of the data obtained from each member facility through the use of data dictionaries, audit and training. As a result, the quality of the data continues to improve, thereby improving the reliability and timeliness of the benchmarking and other information provided by AROC back to the sector.

AROC adopts a number of strategies to improve the quality of the benchmark data it provides and the outcomes of rehabilitation for patients at a facility level:

- data validation checks (discussed under principles 24 and 25);
- constant communication with members;
- provision of training workshops, seminars and conference presentations describing how to collect the AROC data and/or make the best use of the benchmarking information provided by AROC; and
- facilitation of industry based development of outcome targets, and then measurement against and communication of achievements against these targets.

The opportunity to be a pilot site for the testing and validation of the Clinical Registry Operating Principles and Technical Standards is an additional quality assessment that AROC will use to enhance its operational ability and data processing now and into the future.

Principle 24: Australian Clinical Quality Registry data should be checked in a sample of cases. This usually involves audit against source records. The sample size needs to be sufficient to produce reliable measures of data completeness and accuracy. The frequency of audits needs to be sufficient for data quality lapses to be identified promptly. Incomplete or inaccurate data should be identified by the data centre and remedied as soon as possible

Assessment: Relevant – AROC does not comply but would if resources were available.

Barrier: Source data audits are resource intensive

Action: Activity 6 (reported against at Section 7 of this report) of the current project includes an audit of a sample of data provided to AROC against source data at the facility.

All data received by AROC are screened for missing data, errors and inconsistencies. An audit report (described under Principle 25 below) is sent to each facility on receipt of data with a request that highlighted episodes be reviewed, corrected if necessary and resubmitted to AROC.

At present no audit of source data is routinely undertaken by AROC, due in part to this being a resource intensive process and AROC not having the resources necessary to undertake a project of this scope.

As part of this project AROC undertook a field audit of 1% of the data records provided to AROC during 2008. The outcomes of this audit and the learnings for AROC are described in detail in Section 7 of this report. Unfortunately undertaking source data audits is resource intensive and AROC's ability to build such audits into the routine operations of the registry will depend on the availability of resources and funds required to accomplish this.

Principle 25: Australian Clinical Quality Registries should incorporate in-built data management processes such as data range and validity checks

Assessment: Relevant – AROC complies.

Audit reports are produced automatically upon submission of data with Red (fatal) errors and Blue (cross-check) errors identified. The audit report is automatically transmitted to the facility and facilities are asked to review and correct data where necessary and resubmit. See also Principle 24.

A key feature of the upload process of AROC data is that facilities submit the full AROC dataset each time they upload data to ensure that AROC always has the most up to date and accurate data.

Principle 26: Australian Clinical Quality Registry reports should be produced according to a strict timeline and should be appropriately funded to enable this to occur.

Assessment: Relevant – AROC complies.

AROC provides twice yearly reports to member facilities (a calendar year report, and a financial year report, each available within 3 months after the end of the reporting period), analysing their data and comparing them to the appropriate benchmark group data and the

national data. Current benchmark groups are public sector and private sector, although this is expected to expand to also include impairments, e.g. brain injury, spinal cord injury as well as other relevant groupings.

AROC also publishes an Annual Report – The AROC Annual Report: The State of Rehabilitation, which summarises the data received in each calendar year. A copy of the inaugural and latest Annual Report is available through the AROC website <http://chsd.uow.edu.au/aroc/>.

4.7 Organisation and governance

Principle 27: Australian Clinical Quality Registries must formalise governance structures to ensure accountability, oversee resource application, provide focus and optimise output.

Assessment: Relevant – AROC complies.

Recommendation: AROC recommends that the Operating Principles be less specific about the format of the governance structure required (or at least express it as one example), and perhaps concentrate more on the principles that any governance structure should demonstrate, for example, independent oversight.

AROC is a sub-centre of the Centre for Health Service Development (CHSD) and has been operational as a national clinical registry for the past six years. The CHSD is a research and development centre of the Sydney Business School, University of Wollongong (UoW).

The AROC Management Advisory Committee (MAG) is the Steering Committee responsible overseeing the executive management of AROC, including its clinical and scientific governance. The Chair of MAG is an appointment of AFRM. Reporting to MAG is a Scientific and Clinical Advisory Committee (SCAC), which provides advice on matters relating to data and reporting policy, education and training issues and research priorities.

AROC itself is staffed by approximately 5 FTE, headed by an AROC Manager. Staff are employed by the University of Wollongong. As well as being responsible to the AROC governance structure, staff are also responsible to CHSD at UoW.

In addition to the staff of AROC, the CHSD has a network of visiting fellows (about 10 currently active) who work with the Centre on specific projects and working groups. The CHSD staff and fellows have qualifications and expertise in 16 disciplines - psychology, statistics, economics, public health, management, health planning, operational research, education, pharmacy, human geography, health sociology, medicine, occupational therapy, nutrition, nursing and communications.

Principle 28: Australian Clinical Quality Registries must establish policies to manage a range of contingencies arising from the analysis of data from the registry, which includes a formal plan ratified by the Steering Committee to address outliers or unexplained variance, to ensure that quality of care issues are effectively addressed and escalated appropriately.

Assessment: Partially relevant (relevant at facility level, not at episode level) – AROC does not comply at this stage in a formal sense.

Action: AROC, through the Scientific and Clinical Advisory Committee, will establish a policy and process to review individual facility outcome performance, and where such performance falls below an agreed threshold, highlight this fact to senior executives of the relevant facility.

Recommendation: that this Principle be reworded in a more general manner to take account of registries with differing purposes and operational structures.

The principle of registries having a defined process to address quality of care issues identified through analysis of the data is relevant and appropriate. However, AROC receives de-identified episode level data from participants who are facilities, not individuals, and the benchmarking analysis we do aggregates the episode level data. In addition, our purpose has not, to date, included a performance review aspect.

It would not be possible, or appropriate, for AROC to comply with the Principle as it is currently worded. However we do believe it is important for AROC to establish a policy and process which allows us to review individual facility outcome performance, and where such performance falls below an agreed threshold, highlight this fact to senior executives of the relevant facility. The concept has been discussed with the AROC SCAC, and AROC are in the process of developing a detailed proposal for SCAC's consideration.

4.8 Data Custodianship

Principle 29: Custodianship of data needs to be made explicit in Contract and /or Funding Agreements

Assessment: Relevant – AROC complies.

The Australasian Faculty of Rehabilitation Medicine (AFRM) is the auspice body and data custodian. The Centre for Health Service Development (CHSD) at the University of Wollongong is the data manager and responsible for the day to day operations of AROC. The custodianship of AROC data submitted by member facilities is made clear in their membership agreements.

Principle 30: Data access and reporting policies for Australian Clinical Quality Registries should be made available to persons wishing to use register data

Assessment: Relevant – AROC complies.

The AROC dataset is a rich source of information. Apart from the bi-annual benchmarking reports provided to members, and the AROC Annual Report: the state of rehabilitation in Australia, published and available to everyone, AROC encourages clinicians undertaking research in the field of rehabilitation to seek access to analysis of data in the database to support their research interests. At this stage episode level data are not available to access.

Data access and reporting policies are informally utilised at present. The issue has been discussed by the AROC SCAC, and as part of Activity 8 of this project (reported against in Section 9 of this report) these informal policies are being formalised and documented into an AROC Data Policy. In association with the data policy an AROC Data Access Application form and associated guidelines have also been developed. Once finalised, data access and reporting policies will be documented and published.

Principle 31: Third parties wishing to access data and publish findings must seek approval from the Steering Committee and obtain relevant Institutional

Ethics Committee endorsement where identified or re-identifiable data or contact with patients is sought.

Assessment: Relevant – AROC complies.

See Principle 30.

4.9 Ethics and Privacy

As a University research centre, CHSD is responsible to the University of Wollongong Human Research Ethics Committee. University ethics committees enter agreements with the NHMRC to operate within the Councils' framework for the conduct of all research. Therefore, it is mandatory that the UoW HREC complies with obligations under the Privacy Act and guidelines including the 'Australian Code for Responsible Conduct of Research' and the 'National Statement on Ethical Conduct in Human Research'.

Research and project developments (including AROC) that are undertaken under the auspice of the University of Wollongong must submit ethics applications to the HREC and are obliged to provide annual reports to the committee for continuation. In addition, modifications to AROCs protocols that may affect the conduct of the data collection or processing are required to be submitted by the chief investigator for acceptance to the HREC before they can be implemented.

In addition, the Australian Universities Quality Agency (AUQA), which carries out independent quality audits of Australian universities, other self-accrediting universities and accrediting agencies, audited the University of Wollongong in 2005. The audit which included a review of governance committees, including ethical research practice was highly commendable about the university practices and the report was publicly released in March 2006. The CHSD is also a corporate member of the Health Services Research Association of Australia and New Zealand and is a member of the Australian Institute for Health Policy Studies. Both these organisations adhere to and support high level practices in human research.

Principle 32: Institutional Ethics Committee approval must be obtained to establish the Australian Clinical Quality Registry (except where legally mandated or legally authorised)

Assessment: Relevant – AROC complies.

AROC first sought and achieved ethics approval from the University of Wollongong/ Illawarra Area Health Service Human Research Ethics Committee in early 2002, prior to commencing operations. Ethics approval has been continuous from that date.

Principle 33: Registry personnel should be familiar with and abide by the requirements set out in relevant privacy legislation, the National Statement on Ethical Conduct in Human Research and the Australian Code for the Responsible Conduct of Research

Assessment: Relevant – AROC complies.

The CHSD has been involved in a large number of projects requiring collection and analysis of qualitative and quantitative data. Accordingly, AROC personnel are fully aware of the requirements set out in the relevant privacy legislation for the conduct of research and work effectively within a wide variety of interest groups in the health, aged care and community

sectors. The team also have an affiliation with the Faculty of Informatics at the University, who are active advocates for securing information held in large databases.

Principle 34: Participants or their next of kin should be made aware of the collection of register data. They should be provided with information about the Australian Clinical Quality Registry, the purpose to which their data will be put and provided with the option to not participate. This should be at no cost to the registry participant

Assessment: Not Relevant

AROC recommends the expansion of the operating principles to include consent guidelines for the provision of de-identifiable data to clinical registries.

Participation in AROC resides at the facility level, and each member provides de-identified data at an episode level. Therefore AROC does not have a relationship with any individual rehabilitation patient, and thus this guideline is not relevant to the operation of AROC.

Principle 35: Where projects are undertaken using register data, IEC approval must be sought unless the project falls within the scope of an institution's quality assurance activity

Assessment: Relevant – AROC complies.

See Principle 30.

4.10 Information Output

The volume of rehabilitation episodes has been steadily increasing over time, due in part to the ageing of the population, and in part to the fact that the community is better educated, more aware that rehabilitation may allow them to remain independent for longer, and less willing to accept dependence as their lot. Whilst the health sector places significant focus on acute care, and downstream on community care, it is rehabilitation that often provides the connection between those two sectors.

Contemporary rehabilitation is developing new models of care in response to changing patterns of morbidity and changes in the acute care sector. These include early intervention in acute care to prevent complications and maximise function and an increasing role working with older patients with coexisting problems. These patients are traditionally the ones that the health system has difficulty managing. A key feature of this work is its potential to reduce the length of stay for patients in acute care. Rehabilitation, when done well, is starting earlier and not waiting for medical stability to be achieved.

Rehabilitation now has a vital contribution to make across the whole continuum of care:

- Disability prevention;
- Community-based models that substitute for inpatient care or prevent the need for hospital care;
- Chronic disease management;
- Transitional Care;
- Preventing or delaying long term residential care; and
- Re-inventing former roles, particularly in outpatient and community care.

Member facilities value the outcome benchmarking provided by AROC and the registry has received many examples of facilities utilising this information to improve both their practices and the quality and safety of the care they provide.

Principle 36: Data from Australian Clinical Quality Registries should be used to evaluate quality of care by identifying gaps in best practice and benchmarking performance

Assessment: Relevant – AROC complies.

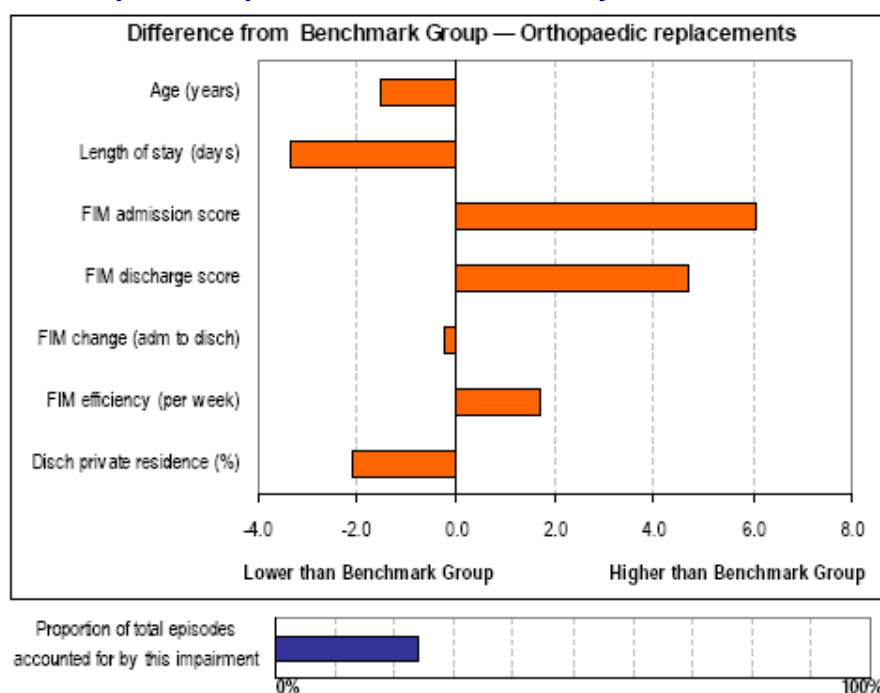
In its benchmark reporting, AROC provides analyses of each member facility’s data, and also compares that data to analysis of the overall sector (public or private), and to the national data. Tables are presented showing the frequency with which each item of the AROC data set is collected at the facility (data quality), and the number of episodes provided for each month (data completeness). An overall facility data quality score is also provided.

Data are casemix adjusted so that facilities can directly compare themselves with other facilities. Casemix adjustment corrects for the different types of cases seen by different facilities.

Rehabilitation episode outcomes are provided to each facility to demonstrate the benchmark group average of the item described, the difference between benchmark group averages and the proportion of the facilities episodes that are classified by the impairment presented.

An example of the benchmark reporting provided to facilities is shown in Figure 3.

Figure 3 *AROC Benchmark reporting showing difference to the average for orthopaedic replacements for one facility*



Source: AROC report --- Anywhere Hospital from July 2007 to June 2008

Principle 37: Australian Clinical Quality Registries must report without delay on risk adjusted outcome analyses to institutions and clinicians

Assessment: Relevant – AROC complies.

AROC benchmarking reports provided to member facilities bi-annually within 3 months of the end of the reporting period. Principle 36 outlines the detail provided in these reports.

Principle 38: Australian Clinical Quality Registries should verify data collected using a formalised peer review process prior to publishing findings

Assessment: Relevant – AROC complies.

This principle is not relevant to the Benchmarking Reports provided to each member facility twice each year. However, it is relevant to The AROC Annual Report: the state of rehabilitation in year (SoN). A draft of the SoN is circulated to a number of rehabilitation clinicians for their review and input prior to the document being finalised. This process is overseen by the Scientific and Clinical Advisory Committee. Ideally the SoN publications are placed in high impact journals that may utilise a peer review process prior to accepting a manuscript for publication. AROC aims to have the SoN for a calendar year published by the middle of the following year; noting however that we have yet to achieve this objective.

Principle 39: Local database managers should have the capacity to undertake ad hoc analyses of their data to enable monitoring of clinical care

Assessment: Relevant – AROC does not currently comply but will comply when the new IT system is implemented.

Action: AROC is building a facility for members to undertake ad hoc analyses of their data after its provision to AROC. These are being built into the AROC Online Services system enhancements. Whilst currently all SNAPshot data managers are able to access their data in SNAPshot most do not have the technical expertise for this facility to be useful for them.

The AROC IT Upgrade will include the capability for members to undertake ad hoc analysis of their data. This project has commenced with completion expected by the end of 2009.

Principle 40: Australian Clinical Quality Registries must produce a publicly-accessible aggregated annual report detailing clinical and corporate findings

Assessment: Relevant – AROC complies.

AROC Annual Report: the state of rehabilitation in Australia is published annually and available on the public domain. The report describes patients discharged from subacute inpatient rehabilitation programs provided by facilities that are members of the Australasian Rehabilitation Outcomes Centre (AROC). The report includes the AROC Data audit process, Assessment using the FIM, AN-SNAP Class commentary of rehabilitation in Australia for that year, outcomes by impairment, change in rehabilitation practice between the year reported and historically and competing interests if any.

Principle 41: Australian Clinical Quality Registries must have documented procedures for reporting on quality of care, including addressing outliers or unexplained variance

Assessment: Relevant – AROC does not currently comply, but is in the process of addressing this..

See Principle 28.

4.11 Resources and Funds

Principle 42: Australian Clinical Quality Registries should be appropriately funded to allow data collection, reporting and the institution of strong quality control procedures.

Assessment: Relevant – AROC complies.

As stated in the background section, AROC is funded by contributions from all rehabilitation sector stakeholders. AROC receives sufficient funds for the core operations, staffing, development of information technology and disseminating the registry findings. Nevertheless, the level of funding has not allowed AROC to undertake additional, non essential, projects, especially relating to quality of data provision through auditing and the development of processes to enable outlier reporting as part of its quality assurance program.

The opportunity to be a pilot site for the testing and validation of the Clinical Registry Operating Principles and Technical Standards will provide valuable resources that AROC could use to enhance its operational ability and data quality processes now and into the future. In the future, it is hoped that core funding for AROC will comprise part of a National Rehabilitation Strategy. The AFRM and AROC have jointly drafted such a strategy and have been lobbying for its inclusion in the new National Health Agreement (NHA) currently being negotiated between the states and territories.

5. Evaluation of AROC and the technical standards (architecture and standards map)

Part B of the Operating Principles and Technical Standards sets out short and long term architecture relevant to Australian Clinical Quality Registries and a standards map that lists the technical standards considered relevant to registries. We have reviewed these goals and have offered some comments about the architecture in the next section (Section 5.1). This is followed by a review of the technical standards as they relate to AROC (Section 5.2).

5.1 The Australian Clinical Quality Registry Architecture (Short and long term)

Not surprisingly AROC does not currently sit within the envisioned short term architecture for clinical registries. However, if a national portal for Clinical Registries was available, AROC would be more than happy to load basic details and a link to the AROC website onto the site. Any additional engagement would require approval through the AROC governance structure, and of course be subject to ethics.

Having said that, AROC believes the short term goal to develop a registry portal for Australian registries is achievable inside the constraints outlined in the technical standards

document. The initial portal could be as minimal or extensive as the governance of each registry will allow. As a first step and to limit the involvement of registries, the scope could be contained to the name of the registry, its purpose and scope, and a link to the registry web site.

Expansion of the national registry portal to include information about registry provider information, participation consent requirements and documents about data capture will enable viewers to access more information but will require acceptance by registry governance bodies and be subject to ethical processes. Furthermore, information about data capture that incorporates links to national standards used by the registry, particularly those listed in MeTEOR would be valuable. A national registry portal could detail any existing differences/restrictions for reporting to national registries that jurisdictions require.

The extent of information supplied about registries in a national portal will rely on issues highlighted in the technical standards such authentication consent and general governance of the registry. AROC sees the benefits in providing viewers with a clear overview of how registries sit within the health care system in Australia and ultimately what their role and inclusion will be as Australia moves forward towards the individual EHR. Having as much information as possible available about the registries will make clearer the sensitive issues around information collection and exchange. Beyond their clinical and epidemiological value and reporting roles, registries often follow-up patients (although this doesn't apply to AROC) and remind them of required tests and help monitor the quality of their care. Consequently, information from registries will become an important aspect of the individual EHR.

It is believed that the Clinical Quality Registry pilot process will promote compliance and willingness for registries to move towards adopting the Operating Principles and Technical Standards. We support having the standards available on the registry portal so that stakeholders wishing to develop registries and maintaining them can do so using the nationally endorsed model. Further, having a registry portal will also foster international comparability and agreement on data definitions particularly where ISO standards, HL7 messaging and other international standards are adopted into registry systems in Australia. One of the barriers currently is that there have been definitional problems in using registry data for international comparisons, because of the different data items and definitions used.

Transitioning registries to the longer term vision described is reliant on a successful E-Health environment. Newly developed registries have the advantage of adopting current standards that will enable interoperability, however, existing registries such as AROC may need considerable modifications which will be costly to implement. As a step towards migration, AROC favours the use of data items in NMDSs and for some time has worked closely with the DOHA and AIHW to include AROC values in MDS. AROC already includes relevant clinical and socio economic classifications developed in Australia to ensure comparative value in a dataset. Investigation and testing of the interrelationship between NMDS, clinical and socio-economic classifications, standard terminologies, IT standards and archetypes will be an integral part of future minimum data set development work in order that registries move towards a compatible platform.

Probably the most critical factor to achieving and sustaining a common registry data collection and linkage within the E-Health environment in Australia, is the need to approach development and migration of systems nationally. As stated in the recently released discussion paper E-Health: Enabler for Australia's Health Reform Prepared for the National Health & Hospitals Reform Commission (2008), Australia needs a collaborative national approach to E-health rather than pockets of development by each jurisdiction. AROC has had firsthand experience of collaborating with the jurisdictions and supports the need for understanding an agreed business case at a national level for the role out of the individual EHR and other initiatives. Alignment of registry data will be best achieved within this context.

5.2 Evaluation of AROC with technical standards

5.2.1 Approach to technical standards review

The standards referred to in the Standards Map are numerous with some referencing other multiple standards. The time, resources and technical expertise required to undertake a comprehensive review of these standards in and their application to AROC is significant. In addition whilst some standards are available in the public domain others must be purchased. For these reasons the review of the technical standards was undertaken in two stages:

Stage 1: Examination of the relevance of the standards to AROC using our prior knowledge, available documentation and understanding of the AROC system architecture and information model. All standards included in the technical standards document were considered in this Stage 1 assessment and reported in AROC's draft report (12 Dec, 2008).

Stage 2: A detailed assessment of the standards identified in Stage 1 as potentially applicable to AROC, including their relevance and likely timeframe of implementation if implementation is seen as desirable. Several Australian and ISO standards were examined in addition to NEHTA standards as part of the process. UoW IT policy documents were reviewed as part of this process.

The results of both these stages are provided in this final report.

AROC does not consider this review of standards as a one off exercise. This is particularly true in instances where the standards themselves are evolving and being updated or adapted to address emerging or local requirements. Moreover, the review has highlighted areas where standards are not only applicable to the registry, but are already in place or relevant to the ongoing safeguarding of AROCs data.

5.2.2 Categorising standards

A Standard is defined as a:—

“document, established by consensus and approved by a recognized body, that provides, for common and repeated use, rules, guidelines or characteristics for activities or their results, aimed at the achievement of the optimum degree of order in a given context” (SAA HB107-1998).

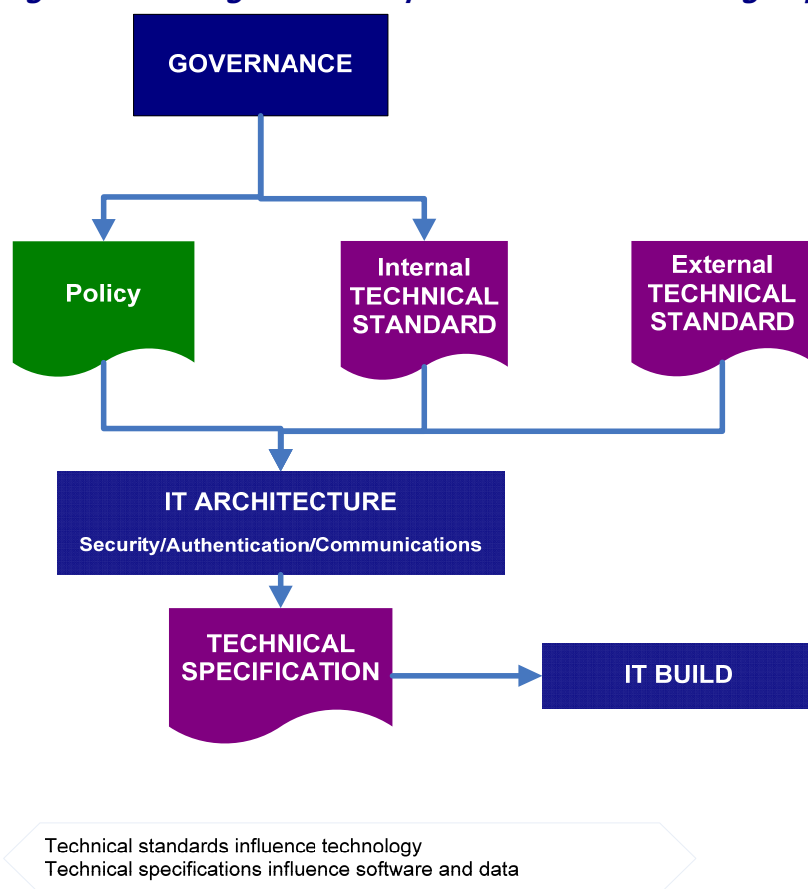
Many of the standards listed in the Standards Map do not fit into the generally accepted standard types noted in HB 107-1998 such as ‘product, ‘design’, ‘safety’ or ‘testing standards’. Rather they are high level standards that focus on recommended ‘guides for use’ and are targeted to the organisational stakeholders and project managers. Nearly all of documents listed fall into this category and are distinguishable from standards that set out data and technical specifications, which prescribe the codes of practice for building information systems.

Organisations such as UoW follow most of these high level standard completely or partially because they set down how IT project managers should develop the framework and application for software development. In other words, these standards are stating what attributes the system should ideally contain (such as security, authentication, terminology) but do not drive the specification of the ‘build’ as such. Use of the technical standard is a management decision, and generally not determined by a software developer or vendor.

High level standards and technical specifications both belong under the standards umbrella, however, we have made this distinction in our review as it impacts relevance of the standards and compliance. Figure 4 shows the high level (or technical standards) and

technical specifications in relation to the organisational processes within a registry. NETHA standards clearly state the intended audiences for this purpose.

Figure 4 *Organisational processes within the Registry to which standards apply*



The characteristics shown in Figure 5 are particularly relevant for AROC because many of the decisions about software architecture, communications and identity management (set out in the Standards Map) are the responsibility of the UoW ITS. The role of the UoW ITS is discussed in the next section.

5.2.3 Standards review in relation to the University of Wollongong IT infrastructure

AROC is a sub-centre within the Centre for Health Service Development (CHSD), University of Wollongong (UoW) under which it is governed. Consequently, many governance processes, including IT infrastructure for CHSD and AROC are regulated by UoW. The UoW IT structure impacts the operational activities of AROC in terms of its database infrastructure, communication security over internet and intranet, files safety and secure access to AROC data by member facilities. Therefore, the decision about use/adoption of many of the technical standards reviewed, primarily those set out under ‘Identity Management’, are and will remain the responsibility of UoW.

Policy on IT is advised to the University Vice Chancellor through the Information Technology Policy Advisory Committee (ITPAC). The Information Technology Services (ITS) implements such policy. The goal of ITS is to deliver technology initiatives that support the Universities “research, teaching and business activities” and provides a “technology infrastructure that is

reliable, sustainable, meets current industry standards, and can rapidly adjust to changing needs” (University of Wollongong, Information Technology Strategic Plan, December 2005). To achieve this, the University ITS must address both the core needs of the University (teaching and research) as well as the individual needs of the centres (such as AROC), and subsequently deliver a system infrastructure that meets all requirements. Balancing the complexities of this task is required by ITS and may necessitate supplementation to the general scope of operations that it handles.

AROC sought to involve ITS experts in the detailed review of the Identity Management technical standards for the pilot project in addition to advice already provided by CHSD’s IT experts and it’s newly formed Australian Centre for Clinical Terminology and Information (ACCTI). In addition, ITS policy documents were reviewed. In Table 2, we have reported on the applicability of the Identity Management standards to AROC, and if known whether they are followed (wholly or in part). However, we were unable to state whether ITS intend to include these standards longer term as this requires further review by ITS which they were unable to complete before reporting. AROC will take into account the inputs from ITS about Identity Management processes once they are provided.

5.2.4 Currency of standards reviewed

For the pilot study review, AROC evaluated all standards in the Standards Map current as at January 2009. As alluded to in the introduction to the Standards Map document, standards are often changed or revised, especially where local standards are developed from international versions. One major impetus for change in the current environment relates to the nature of E-Health development. For example, the technical standards and specifications (particularly those relating to clinical communications, messaging and identity management) will continue to develop in line with the focus and scope of E-Health. Many countries, like Australia, are continually reinventing frameworks as part of their E-Health and EHR strategy. For standards development, this means that many are not mature in their content and are initially developed with a limited use case or scope. A good example of this is NEHTAs Discharge Summary data specification. This standard is not yet ratified and the use case specifically applies to acute care for HL7 messaging. This means that the specification is relevant to HL7 messaging (or point to point event based communication), rather than for broader patient based data collections, such as registry data.

AROC understands the need to trial standards in the appropriate domains, yet such uptake would be more desirable on tested content and on the basis of understanding cross standard interdependencies. Moreover, in the context of the ever changing E-Health environment described above, we would be cautious about implementing many of the data specifications for the current collection, but rather build them into a forward plan so that AROC data can be aligned with standards as they achieve wider acceptance and or adoption.

5.2.5 Standards compliance

AROC has been an established registry for 7 years which receives contributions from 165 member facilities in Australia and New Zealand. The operating and functional aspects of AROC define this registry as a Level 2 registry. Specifically, AROC members submit their data via AROC Online Services onto the registry database. It is a ‘one-way’ submission process as described in the NeHTA Standards Map in the Operating Principles and Technical Standards for Australian Clinical Quality registries.

One of the clear outcomes of the review was that AROC follows (or complies) with many of the standards recommended for a Level 2 clinical registry. However, it is necessary to define

what we mean by 'compliance' here. Firstly, many of the standards listed fall into the category of 'mandatory' or 'performance' standards. These are standards where all of the documented content does not necessarily need to be followed even though they are prescribing the best approach. In particular, performance standards are quite 'loose' as they can be developed with very broad outcomes (SAA HB107-1998). Many of the technical standards in the Standards Map fall into this category. Secondly, some of the more prescriptive standards listed may give a range of content that is not entirely relevant to the organisation. For example, if a clause on web services is mentioned in a standard on data security, but the organisation does not have that specific web service, it does not mean that the organisation doesn't follow the security standard, but rather that the web service aspect of the standard does not apply. In this environment, the standards become recommended guides, rather than a tick box of do's and don'ts. Therefore, when we use the term 'compliance' it does not mean that AROC or the UoW follows each standard verbatim, but that the rules, requirements and guidelines stipulated by a standard have been met overall. The standards were reviewed for the pilot process within this construct.

It is also worth commenting that in the larger IT arena of the University, many of the architectural framework and identity standards may be relevant, but not necessarily practical to adopt. Where an information system has been in place for sometime and functionally interoperable, reengineering or reconfiguring to achieve compliance with recognised standards would not necessarily be desirable as it would pose considerable cost in infrastructure changes and upgrades. Nonetheless, AROC does recognise there are opportunities for considering many of the standards in the new build of its databases to obtain better alignment.

5.2.6 Table showing relevance of technical standards to AROC


Table 2 outlines our review of the standards and includes comments relating to AROCs ability to adopt these standards. IT related standards that require ongoing contributions from key stakeholders at UoW have been identified.

The table is set out according to the NEHTA domains as outlined in the Standards Map in the "Operating Principles and Technical Standards for Australian Clinical Quality Registries" (refer to Table 6, pg 95). We have listed in the table whether each standard is relevant to AROC in the context of its one-way web-based submission process and if relevant, whether AROC currently complies with the standard or intends to comply in the future. Likely timeframes associated with implementation are indicated.

Table 2 Overview of the technical standards and their relevance to AROC

⇒ Standards NEHTA recommended domains	Level 2 One-way submission	Specific Standard name	Relevance to AROC/ timeframe to comply	Comments on compliance
Interoperability Framework (eg. Architecture)	Optional	Interoperability Framework 2.0	Not relevant	<p>The Interoperability frameworks presented relates to a two way linkage of automated data collection – in line with the longer term architectural vision outlined in Part B of the operating principles and technical standards.</p> <p>This standard is the model overview (ie infrastructure) whereas the others listed below are the detail to support the implementation of such an infrastructure.</p> <p>Currently, the AROC upload process does not match these standards. Considerable migration steps would be required to have an existing registry such as AROC adopt the framework for national infrastructure.</p>
	Not required	Unified Modelling Language v2.0	Relevant	<p>UML is a language that effectively assists to build a software system by describing the requirement and model structure and the behaviour relationships. This is achieved via a series of software diagrams that are used between software developers and system architects.</p> <p>In the technical standard, NEHTA recommended that the UML should be use as a modelling notation. AROC is currently using and continuously using UML to model the system as it is the most widely used modelling language which easy to be shared.</p> <p>However, AROC have a concern about the inclusion of UML in the interoperability framework section in the technical standard, Compared with other frameworks such as TOGAF, UML is not a framework but a real technology which might fit more appropriately in a different section of the technical standards.</p>
	Optional	TOGAF “Enterprise Edition” v8.1 The Open Group Architecture Framework (TOGAF)	Not relevant	<p>The TOGAF is a set of supporting resources and detailed methodology for developing an enterprise architecture. The current version is TOGAF 9.</p> <p>AROC is a sub centre of CHSD and the current data collecting and reporting system is very specific. TOGAF is not relevant to AROC as it is very difficult to apply such a complex and systematic framework on currently limited IT resources. However, it is possible to apply TOGAF for future CHSD enterprise level system development in order to coordinate various programs, projects and resources.</p>
Information Technology – Open Distributed Processing	Optional	ISO/IEC 15414:2006 Information Technology - Open Distributed Processing - Reference Model - Enterprise Language ISO/IEC 10746-1:1998	Not relevant	<p>ODP has been developed to standardise open system interconnection (or OSI) - it is the standard for worldwide communications that defines a framework for implementing protocols.</p> <p>The main driver of ODP is the: ‘transparencies’ which have been developed</p>

⇒ Standards NEHTA recommended domains	Level 2 One-way submission	Specific Standard name	Relevance to AROC/ timeframe to comply	Comments on compliance
		<p>Information Technology - ODP - Reference Model: Overview - Part 1</p> <p>ISO/IEC 10746-2:1996 Information Technology - ODP - Reference Model: Foundations - Part 2</p> <p>ISO/IEC 10746-3:1996 Information Technology - ODP - Reference Model: Architecture - Part 3</p> <p>ISO/IEC 10746-4:1998 Information Technology - ODP - Reference Model: Architectural Semantics - Part 4</p>		<p>to provide users and programmers with a <i>uniform</i> view of any system. An example of a distributed site is the ability for more than one person to work on the same software.</p> <p>ODP is useful for the collaboration between different development sites – such is required when developing terminologies internationally.</p> <p>As the national rehabilitation data collection and research centre, AROC will obviously need to operate within an interoperability framework to enable effective communication with other national and international collaborators at a data level in the future.</p> <p>In terms of the border frameworks listed in this technical standard, AROC would recommend that a customised and integrated standard framework specific for Australian Clinical Quality Registries be developed and released.</p>

 Standards NEHTA recommended domains	Level 2 One-way submission	Specific Standard name	Relevance to AROC/ timeframe to comply	Comments on compliance
Clinical Communications	Required	IHTSDO 0109_07:2007 SNOMED CT® International Release (UK Language Edition) – document released July 2007 SNOMED CT updated, January 2009 The latest version of SNOMED will be used if AROC decide to adopt any content. If SNOMED is used by a member facility, the version should be the same to support semantic interoperability.	Relevant – many of the data values in AROC match the content of SNOMED, however, the use of SNOMED for the data collection requires further research and feasibility before uptake Beyond 12 mths	The International Health Terminology Standards Development Organization (IHTSDO) is the organisation that owns and manages the ongoing development of SNOMED CT. NEHTA have identified the Systemised Nomenclature of Medicine, Clinical Terms (SNOMED CT) as the preferred national terminology for Australia and as a member of IHTSDO is responsible for developing its content and extensions in Australia. Although inclusion of SNOMED CT terms as a subset or extension terminology for the rehabilitation sector is desirable, there are some barriers to its implementation that we have identified below. AROC recommends that further study be undertaken to address the feasibility of SNOMED CT for the rehabilitation sector. 1) As NEHTA points out, SNOMED does not cover all the terms and concepts relating to every health domain - the non-acute sector is particularly relevant to this point. To date, the development of SNOMED CT for the Australian health care system has targeted areas such as medicine, devices, pathology and diagnostic imaging. Further work will be required to evaluate SNOMED for rehabilitation medicine as well as the relevance and cost effectiveness of its implementation in the sector. 2) SNOMED CT architecture (i.e. both its structural and content features) will impact functional interoperability and semantic interoperability respectively, where they are required. Understanding the SNOMED CT architectural model in this context is important and will require considerable review. Although matching AROC data at the concept level with SNOMED CT is important, it is just part of a larger process that will be required to ensure successful implementation. 3) AROC is a national collection and implementation of a standard terminology would require national role out to all member facilities. Integration of even a small subset or extension of SNOMED CT would be a large undertaking in light of the variations in existing information systems.
	Required	NEHTA 0013:2006 Medication Data Specifications v1.0 NEHTA 0032:2006 National Discharge Summary Data Content Specification v1.0 NEHTA 0058:2007 General Practitioner and Specialist/Critical Care Referral Data Content Specifications v1.0 NEHTA 0082:2007	Relevant - AROC comply - ongoing	Three of the listed data specifications are relevant to AROC data collection: <ul style="list-style-type: none"> • NEHTA 0138:2007 Observation Data Specification v1.0 • NEHTA 0139:2007 Problems and Diagnosis Data Specification v1.0 • NEHTA 0140:2007 Reason for Encounter Data Specification v1.0 AROC comply with the general framework of the above named standards.

⇒ Standards NEHTA recommended domains	Level 2 One-way submission	Specific Standard name	Relevance to AROC/ timeframe to comply	Comments on compliance
		Pathology Data Specification v1.0 NEHTA 0093:2007 Diagnostic Imaging Data Specification v1.0 NEHTA 0133:2007 Adverse Reaction Data Specification v1.0 NEHTA 0134:2007 Alert Data Specification v1.0 NEHTA 0135:2007 Clinical Intervention Data Specification v1.0 NEHTA 0136:2007 Clinical Synopsis Data Specification v1.0 NEHTA 0137:2007 Immunisation Data Specification v1.0 NEHTA 0138:2007 Observation Data Specification v1.0 NEHTA 0139:2007 Problems and Diagnosis Data Specification v1.0 NEHTA 0140:2007 Reason for Encounter Data Specification v1.0.		It is appropriate for AROC to take these standards into consideration when building our information system in terms of supporting national data collection and knowledge sharing. For example, the integrity of the data model and its value will be reviewed for supporting the data elements in the specification.
HL7 Messages	Not required	Health Level Seven (HL7) standard messaging	Not relevant	The reason HL7 is not required for a one way data submission is that HL7 messaging is used for formalising the semantic exchange of information within an agreed architecture – it places the clinical data into a format or protocol that is readable by many (a point to point event). For example an email is a point to point exchange of data. Uploading data contained in a database is different as it is a persistent store of information (in an agreed format), but not a point to point single message exchange of clinical information.
Datatypes	Required	ISO/IEC 11404 Information technology -- General-Purpose Datatypes (GPD)	Relevant – AROC complies	The AROC data element definitions utilise general purpose data types. The used data types have been implemented in the AROC online services application which is developed by JAVA programming language and Microsoft SQL server. AROC follows this standard and uses the programming language and the general purpose data types in ISO/IEC 11404 Information technology -- General-Purpose Datatypes (GPD). Therefore the standard is and will be implicit in the application. However, from the contents in the technical standard perspective, the data type really depends on the organization's requirement to store and use the data effectively. This requirement is defined in the data specification section of the technical standards, and will therefore guarantee the interoperability implicitly. So a data type

⇒	Standards NEHTA recommended domains	Level 2 One-way submission	Specific Standard name	Relevance to AROC/ timeframe to comply	Comments on compliance
					section might not need to included.
	Health Care Provider Identification	Required	AS 4846-2006 Health Care Provider Identification	Relevant – AROC complies with standard and will implement national provider numbers - next 12 mths	<p>The standard provides both a framework and specifications for data items that best capture information and identify health care settings.</p> <p>AROC complies with this standard in terms of capturing appropriate information for identifying the health care settings of member facilities.</p> <p>The standard includes how the provider identifier should be structured and named and as well as the minimum information required for this purpose.</p> <p>When AROC began, providers gave their own ID but when AROC migrate to the new IT system they will migrate to the national provider number system.</p> <p>This standard will also be useful for the ambulatory dataset.</p>
	Health Care Client Identification	Optional	AS 5017-2006 Health Care Client Identification	Not relevant - development of standards for use of the UHI within a de-identified database would be relevant.	<p>The purpose of this standard is to specify how to appropriately identify individuals for clinical and administrative data management purposes. AROC does not collect patient identifiable information and hence the standard is not applicable – AROC data are de-identified episodes. Refer discussions under Principles 13 and 14 in Section 3.</p> <p>Once the process for inclusion of the UHI in Australia is understood and policies are in place for its provision by the jurisdictions, AROC would be able to maintain the UHI as a data item.</p>

⇒	Standards NEHTA recommended domains	Level 2 One-way submission	Specific Standard name	Relevance to AROC/ timeframe to comply	Comments on compliance
Identity Management	Authentication Assessment Methodology	Optional	Authentication Assessment Methodology v1.0	Relevant – UoW probably comply but the standard is not referenced in policy documentation – ITS to advise	<p>The UoW ITS operates under a set of IT policy documents for the development, implementation and user authentication for IT services. Policy's relevant to the standards included under identity management include:</p> <ul style="list-style-type: none"> • General IT Acceptable Use Policy • Email Access Policy • Internet Access Policy • User Account Management Policy • Web Proxy Policy • IT Security Policy • IT Server Security Policy • Rules Governing Use of IT Facilities • 'All' Mailing Lists Management Guidelines • User Account Management Guidelines • Internet Access Guidelines • Software Asset Management Guidelines <p>AROCs authentication practices are driven by the standards and practices of the UoW IT platform. Authentication is followed at the university and noted in several policy documents. However, specific reference to this standard is not noted.</p> <p>This standard specifically relates to how the security for E-Health data is set up by an organisation. AROC intend to comply with this and include the standard as part of the data policy given it is relevance to their core data. In addition, it is significant for the IT changes for AROC as these will change current practices substantially in terms of online electronic data capture and/or external validity checks. AROC will continue to work with UoW ITS on these matters.</p>
	Framework for Analysing, Planning and Implementing Identity Management	Optional	Framework for Analysing, Planning and Implementing Identity Management v1.0	Not relevant – but may become important if a two way exchange of data transpires.	<p>This framework is the master for E-Health strategy. NEHTA sees Identity Management (IdM) as:</p> <p><i>"an integrated system of policies, processes, and technologies that enables health organisations and the E-Health Community as a whole to facilitate and control users' access to applications and information resources while protecting confidential personal and business information from unauthorised users."</i></p>
	Identity Management resource Set	Optional	NEHTA 0100:2007 Identity Management Resource Set Building Blocks Layer v1.0 NEHTA 0101:2007 Identity Management Resource Set Guidelines Layer NEHTA 0102:2007 Identity Management Resource Set Standards Layer v1.0 NEHTA 0103:2007 Identity Management Resource Set Templates Layer v1.0	Relevant – UoW probably do not comply as new standards from NEHTA	<p>The identity management resource set go hand in had with the framework described above. In the standards map, many standards are listed relevant to the IDM set..some of these are listed below such as:</p> <ul style="list-style-type: none"> • IETF RFC 3076:2001 Canonical XML Version 1.0 • IETF RFC 3275:2002 (Extensible Markup Language) XML-Signature Syntax and Processing <p>AROC suggest that UoW ITS have not implemented these standards as they appear to be the new IdM initiative from NEHTA which are likely untested at present.</p>
	AGAF	Optional	The Australian Government e-	Relevant – AROC utilises	This standard relates to health providers. Electronic authentication (or "e-

⇒ Standards NEHTA recommended domains	Level 2 One-way submission	Specific Standard name	Relevance to AROC/ timeframe to comply	Comments on compliance
		Authentication Framework (AGAF) for Business standard (AGIMO AGAF:2005)	UoW authorisation and authentication policy - ITS will advise on AGAF for their systems	<p>Authentication") is the process of determining the degree of confidence that can be placed in assertions that a user or identity is who and/or what they purport to be. Assertions include identity, role, delegation and value.</p> <p>e-Authentication is accomplished using something the user knows (e.g. password, secret questions and answers), something the user has (e.g. security token) or something the user is (e.g. biometric), or a combination of these.</p> <p>Authentication is not the same as authorisation, which addresses the permissions or privileges granted to an end user to access particular systems, receive particular services or lodge particular reports etc. The issue of authorisation is not addressed in the NeAF.</p> <p>AROC utilises authentication and authorisation practices. The authorisation privileges are at the university level but member providers need an ID and password to access the system (both for upload of data or download of reports). The new system enhancements will see an expansion of authentication and authorisation.</p>
ACSI 33	Optional	The Australian Government Information and Communications Technology Security Manual (ACSI33)	Relevant – AROC do not comply but may in the future – UoW ITS to advise	<p>ACS133 deals with the system security.</p> <p>Whilst AROC do not comply at present with this standard, it will consider this in the future. For example, AROC have technical security but not security that relates to data policy, which is what this standard addresses. AROC will discuss relevance for the future with UoW ITS.</p>
Security Techniques	Optional	<p>AS/NZS ISO/IEC 27001:2006 Information technology - Security techniques - Information security management systems</p> <p>AS/NZS ISO/IEC 17799:2006 Information technology - Security techniques - Code of practice for information security management</p>	Relevant – AROC comply as UoW codes of practices include these standard security mgt	<p>These are the IT related standards for identity management.</p> <p>AROC may comply generally as UoW ITS data security policies embrace many of the codes of practices and security management in these standards.</p> <p>As all the AROC applications are or will be managed by ITS, the data security would be guaranteed.</p>
OASIS eXtensible Access Control Markup Language (XACML) TC	Optional	OASIS XACML (Extensible Access Control Markup Language) v2.0	Relevant – AROC does not comply but UoW use similar technology	<p>This is an IT implementation technical standard. It is specifically designed technology to ensure the access control technology – there are other technical standards to serve the same purpose.</p> <p>AROC does not comply with this standard specifically but the UOW ITS uses a similar standard when developing the intranet system for students and staff to ensure security across different applications.</p>
OASIS Security Services (SAML)	Optional	OASIS Security Services (SAML) TC v2.0	Relevant – UoW probably comply in part in their relevant policy	The UoW ITS policies address user authorisation in their IT Security, IT Server Security and Web Proxy Policies.

⇒	Standards NEHTA recommended domains	Level 2 One-way submission	Specific Standard name	Relevance to AROC/ timeframe to comply	Comments on compliance
				documents – ITS to advise	
Secure Messaging	Web Services	Not required	NEHTA 0009_2.0:2006 Web Services Standards Profile v2.0 NEHTA 0033:2006 Technical Architecture for Implementing Services v1.0 NEHTA 0067:2007 Guidelines for Implementing Interoperable Web Services v1.0 OASIS WS-Security 1.1:2006 Web Services Security: SOAP Message Security 1.1 (WS-Security 2004).	Not relevant.	Currently, there is not a web services related application in AROC. In the future, a web based application is planned, but does not involve web services technology
	XML	Recommended	IETF RFC 3076:2001 Canonical XML Version 1.0 IETF RFC 3275:2002 (Extensible Markup Language) XML-Signature Syntax and Processing	Relevant – AROC do not comply but will plan to in the next 12 mths	In information technology, canonicalization is the process of making something canonical - that is, in conformance with some specification. To canonicalize is to ensure that data conforms to canonical rules, and is in an approved format. It is used for a variety of computer and Internet-related applications. Currently AROC data are in fixed ASCII text format and the process and software are not related to XML. However, in the future system, the XML will be used broadly in both direct ways and indirect ways.
Supply Chain	Supply Chain	Required	NEHTA 0090:2007 E- Procurement Business Architecture v1.0 NEHTA 0088:2007 E- Procurement Technical Architecture v1.0 NEHTA 0131:2007 Addendum to NEHTA's E- Procurement Technical Architecture v1.0 NEHTA 0091:2007 E- Procurement WSDL v1.0	Not relevant	The e procurement technical standards do not apply to AROC as the registry does not record any information on products.

⇒	Standards NEHTA recommended domains	Level 2 One-way submission	Specific Standard name	Relevance to AROC/ timeframe to comply	Comments on compliance
Engagement & Adoption	Understanding Standards	Optional	HB 107-1998 Understanding Standards	Relevant	<p>The objective of this document is to “ help the user to comprehend and interpret the requirements, recommendations and associated matter to be found in Standards, so that Standards Australia publications can achieve maximum effectiveness.” HB 107-1998.</p> <p>The Handbook references the more traditional standards for product design and safety. Some guidelines for IT standards would be useful.</p> <p>AROC referred to the Handbook for the evaluation of standards for this review. The standard will be included in the AROC data policy for user reference.</p>
	CGOI and Communication Technology	Optional	AS 8015-2005 Australian Standard for the Corporate Governance of ICT	<p>Relevant – UoW adopt change mgt processes but do not reference this standard in their strategic plan or policy on IT.</p> <p>To be followed up with UoW ITS.</p>	<p>Includes “guiding principles for Directors of organizations (including owners, board members, Directors, partners, senior executives, or similar) on the effective, efficient, and acceptable use of Information and Communication Technology (ICT) within their organization.”</p> <p>Change management is important in the IT system because (as this standard prescribes), it is important to define what the changes are and how these will be managed, over and above the change process itself. The standard provides recommendations for all the aspects of change management for the whole IT environment and is relevant to any IT system.</p>

6. Activity 5 – Development of the AROC Data Dictionary

6.1 Background

The draft Operating Principle 12 explicitly states that a data dictionary is a critical component of a clinical registry and that a registry must use data dictionaries when they are established to ensure that a systematic and identical approach is taken to data collection and data entry. The Principle states that the objectives of a data dictionary are:

- Establish a core set of uniform definitions relating to the field;
- Promote uniformity, availability, reliability, validity, consistency and completeness in the data;
- Accord with nationally and internationally agreed protocols and standards, wherever possible; and
- Promote the standard definitions by making them readily available to people involved in the collection and use of the data from the data source.

AROC has committed substantial resources to working with the Australian Institute of Health & Welfare's National Data Development and Standards Unit in an attempt to utilise METeOR to construct a Data Set Specification for the AROC inpatient dataset for inclusion in the National Health Data Dictionary (NHDD). Whilst this has been a useful exercise it has not yet been successful, nor resulted in a data dictionary that is useful in an operational sense for AROC members.

This activity involved the development of an AROC data dictionary for both the inpatient and ambulatory datasets. It is envisaged that upon completion the Data Dictionary will be comprehensive and sustainable. It will be flexible and designed to suit a range of users and uses. It will enhance consistency and accuracy, and will facilitate easier ongoing development, versioning and update releases.

6.2 Development of Data Dictionary Structure

A list of metadata items has been developed to define and give guidance on the use of each of the items in the AROC data set collections. A document introducing data dictionary and metadata items has been developed and is provided as Appendix 1 – AROC Clinical Data Set - Data Definitions and Guidelines.

Information to create the AROC data dictionary was gathered from a number of sources including; the original data sets specification documents, AROC training material, SNAPSHOT guidelines, earlier work done to align AROC Data Set with METeOR and the AROC scripts used for statistical analysis and data reporting. This documentation not only dictated the design of the metadata items, but also informed the creation of an information model and database to store metadata for each item (or data element) in the Data Sets. Some of the source information was suited to use by data collectors, while other portions of the source information was particularly useful for information systems technicians.

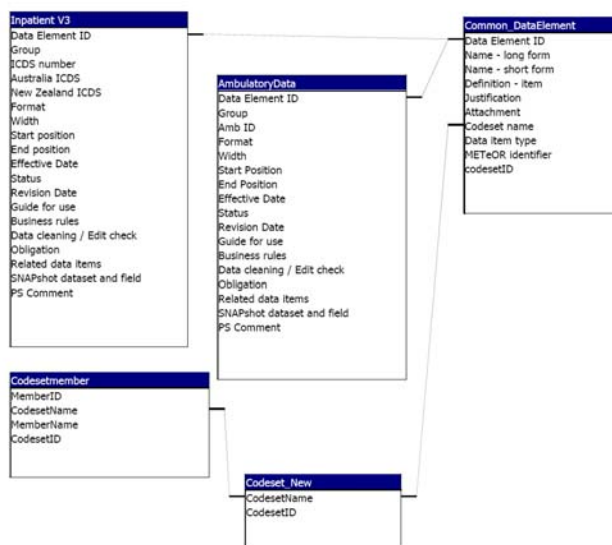
The focus of this Activity 5, from an AROC point of view, was to create a data dictionary that was directly relevant to AROC and therefore practically applicable for the various, and different AROC users. This is the first attempt to systematically bring together all definitions and guidelines relating to the AROC Data Sets. While we did refer to the National Health Data Dictionary we did not merely replicate its structure nor try to mould AROC items into existing NHDD definitions.

The objectives of the Data Elements database design included functions to:

- store information on all data elements in one database
- link shared data elements to more than one Data Set, for example Sex and Date of birth are common to all three AROC Data Sets
- uniquely identify different data elements to allow extraction of information by version and individual Data Set
- extract user-defined information reports/outputs to suit different uses, for example a user guide for AROC data collectors, a format specifications document for data managers
- render information from the database into different mediums; PDF document, MS Word format, HTML
- integrate data into larger CHSD information architecture (future proofing for the AROC IT Upgrade Project)

Figure 5 provides a schematic of the Data Element Database.

Figure 5 AROC Data Dictionary Data Element Database Schema



Tables Description

Table Name	Description
Common_DataElement	This table records all generic data elements appearing in all datasets, each data element has unique ID.
Inpatient V3	Includes all data elements in Inpatient version 3 dataset, each data element inherits attributes from “Common_DataElement” table and has its own attributes in inpatient dataset, such as “ICDS Number”
Ambulatory Data	Includes all data elements in Ambulatory Version 1 dataset, each data element inherits attributes from “Common_DataElement” table and has its own attributes in Ambulatory dataset, such as “Amb ID”
Codeset_New	Records all the codeset names with unique codeset ID, one generic data element could have no or one codeset.

Codesetmember	Records all the codeset members, one codeset could have no member or many members.
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The first draft of the Data Elements Database together with a first draft of the metadata content for the Australian and New Zealand Inpatient Clinical Data Set and the Ambulatory Clinical Data Set was submitted to a thorough review of content before finalisation.

6.3 Data Elements

Appendix 4 provides a print out of the data elements contained within the Data Element Database.

Further extension and enhancement of the AROC data dictionary is possible through the specification of derived data elements. Unlike data collected at the clinical source, derived data elements are calculated or constructed through the use of (sometimes) multiple data elements. For example, analysts might construct a measure of functional improvement over the course of a rehabilitation episode by using 4 'foundation' data elements of episode start and end dates, and functional assessment measures at these two time points (ie: FIM plus episode start date MINUS FIM plus episode end date = functional improvement achieved by this treatment).

Derived data elements are especially useful for analytic and reporting purposes; they are capable of providing additional information, and therefore achieve increased utility and benefit from the data collection, without imposing additional data entry burdens on data collectors.

At this stage, attention has been dedicated to the data elements collected by these stakeholders. Derived data elements will be subject to further development during the next phase of work along with specification, design and testing of content extraction for different users, to provide different views or renditions of the data dictionary

6.4 Next Steps

Substantial progress has been achieved in developing a flexible and comprehensive data dictionary for AROC. Work to date represents the initial foundation which will support further utilisation of AROC data elements and codesets.

The broad and consistent use of AROC data elements, codesets and the data collection itself relies upon the contributions of various stakeholders and agencies. Each of these participants has a slightly different perspective, their practices and requirements vary.

We can imagine that clinical users and data collectors will have a prominent and primary need to understand data element definitions and their guides for use, so as to unambiguously understand the nature and purpose of the information they are collecting.

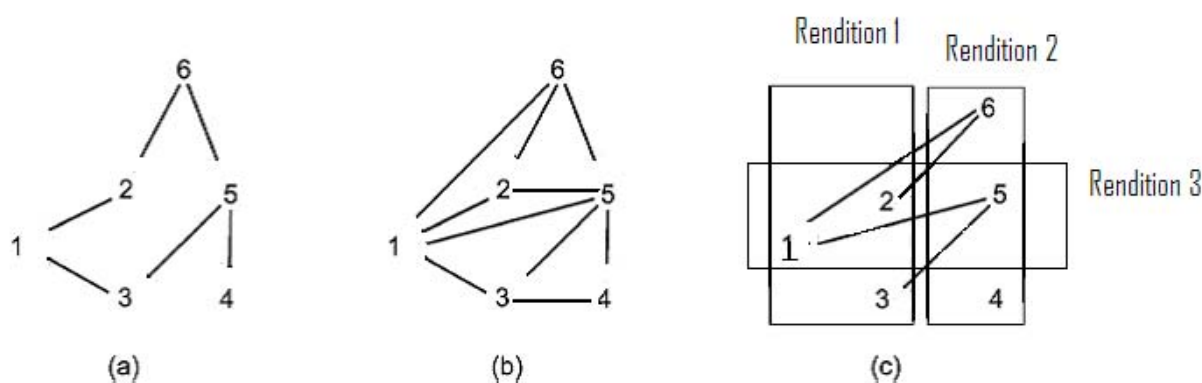
Information technology practitioners, database managers, or application designers will need to understand different features of the AROC data elements. For instance, the datatype characteristics, whether these are alpha numeric or text strings, the length and position of the data fields, the forms and formats of dates and codes, and the relationships between these data elements, will determine how well these data elements can be implemented in, or extracted from, data entry or collection systems.

Data analysts and those stakeholders who are reviewing performance or outcomes will need to be able to understand and use the data elements, in a precise and meaningful fashion, to derive or calculate additional data, not collected at the clinical source.

It is clear that there are at least three, perhaps more, different perspectives and requirements for the use of the AROC data dictionary. We call these renditions. These can be understood as different views, filters or layers, which will be constructed using the existing AROC data dictionary foundations.

Figure 6 shows schematically the AROC data dictionary as it is at this stage (step a) and potential renditions which can be specified to serve different users or uses (step c). This approach maximises data consistency, providing a shared understanding of rehabilitation data and how to use it in a compliant fashion.

Figure 6 Schematic of AROC Data Dictionary



adapted from MEDINFO 2007 K. Kuhn et al. (Eds), **A New Machine Learning Classifier for High Dimensional Healthcare Data** Rema Padan^a, Xue Baia,^b and Edoardo M. Airoldi^b, *a: The H. John Heinz III School of Public Policy and Management, Carnegie Mellon University, U.S.A. b: Center for Automated Learning and Discovery, Carnegie Mellon University, U.S.A.*

Step b here represents the tasks and processes which comprise our next developmental steps. This involves the full specification of different perspectives and requirements so that suitable views can be *rendered* from the AROC data dictionary. Once specified and designed, there will be technical build tasks undertaken to automate these renditions and make them visible and accessible to the community of interest. Options here include hyperlinked pdf documents, web-based access and navigation, subsetted extracts to support training or accreditation purposes, or to provide standard technical specification to IT practitioners or users of SNAPshot.

7. Activity 6 – Development of the AROC Quality Assurance Plan

7.1 Background

Principle 24 explicitly states that Clinical Quality Registry data should be checked in a sample of cases, usually involving an audit against source records. This is as part of a broader requirement to ensure data quality. The potential use of registry data for benchmarking outcomes, assessing compliance and undertaking analysis behoves the need for a registry “to maintain the confidence of providers and consumers in the accuracy and reliability of the information provided”.

Principle 23 states that Clinical Quality Registries should have a robust quality control plan which allows ongoing monitoring of the completeness and accuracy of the data collected. As discussed in the First Report, AROC has incorporated a focus on data quality in its operating procedures but does not have a specific Quality Assurance Plan.

AROC seeks to reduce the variability in content and quality of the data obtained from each member facility through the use of data dictionaries, audit and training. As a result, the quality of the data continues to improve, thereby improving the reliability and timeliness of the benchmarking and other information provided by AROC back to the sector.

AROC adopts a number of strategies to improve the quality of the benchmark data it provides and the outcomes of rehabilitation for patients at a facility level:

- data validation checks All data received by AROC are screened for missing data, errors and inconsistencies. An audit report is sent to each facility on receipt of data with a request that highlighted episodes be reviewed, corrected if necessary and resubmitted to AROC.
- constant communication with members;
- provision of training workshops, seminars and conference presentations describing how to collect the AROC data and/or make the best use of the benchmarking information provided by AROC; and
- facilitation of industry based development of outcome targets, and then measurement against and communication of achievements against these targets.

However prior to this project no audit of source data has been undertaken by AROC, due largely to this being a resource intensive process and AROC not having the resources necessary to undertake a project of this scope.

As part of this project AROC proposed to undertake a field audit of 1% of the data records provided to AROC during 2008 and building on the findings of the audit, develop a specific AROC Quality Assurance Plan.

7.2 Data Audit Scope

The selected target group resulted from a review of overall data quality for all facilities that submitted data to AROC for benchmarking during 2008. Whilst data audits should cover all units reporting data, they can be targeted to areas where data quality problems are evident. This is the approach taken here; the selection process focussed on facilities that were shown to have poor or inconsistent data quality generally across the data items collected, and those identified with unsatisfactory data quality in the key clinical and outcome data items. As part of the six monthly AROC benchmarking reports facilities are given a data quality score that is derived from the frequency with which they complete each data item for each episode of care that they provide data against.

Table 3 details the scores achieved for each of the last three half years for the facilities that will be invited to participate in the audit. Whilst some facilities appear to have high scores, it is key clinical and/or outcome data items that are poorly collected.

The target group represents roughly 15% of all records submitted to AROC for 2008, and covers facilities across a variety of states, sectors and data entry software. The project aims to audit at least 1% of annually reported records. Twenty-five data records were randomly selected for each facility in the target group.

Table 3 *Data Quality Score of Facilities Invited to Participate in Data Audit*

	Data Quality Score Dec08	Data Quality Score Jun08	Data Quality Score Dec06
Hospital 1	95.4	92.8	98.2
Hospital 2	94.9	75.7	95.4
Hospital 3	94.2	87.4	99.4
Hospital 4	94.2	88.0	89.8
Hospital 5	94.2	83.3	89.8
Hospital 6	93.6	87.5	72.0
Hospital 7	93.5	78.4	86.8
Hospital 8	91.4	84.0	85.0
Hospital 9	91.2	77.2	75.2
Hospital 10	90.8	83.0	95.7
Hospital 11	90.0	86.3	70.2
Hospital 12	87.9	83.2	71.2
Hospital 13	87.0	68.6	
Hospital 14	86.6	73.5	99.4
Hospital 15	85.8	90.7	97.0
Hospital 16	85.4	91.3	98.0
Hospital 17	84.7	76.1	76.7
Hospital 18	84.6	91.0	68.5
Hospital 19	83.6	91.5	98.2
Hospital 20	82.0	86.4	77.6
Hospital 21	81.2	79.5	79.0
Hospital 22	80.7	76.3	70.6
Hospital 23	80.7	83.0	79.1
Hospital 24	78.8	88.1	70.5
Hospital 25	77.3	63.2	81.4
Hospital 26	69.3	70.3	81.0
Hospital 27	67.2	61.7	88.5
Hospital 28	51.4	43.3	56.0

7.3 *Data Audit Invitation to Participate*

Facilities were sent a letter inviting them to participate in the audit. A copy of this letter can be found at Appendix 2. Those sites that accepted the invitation were visited by an AROC staff member who conducted the audit. The objective was that for each of the randomly selected 25 records AROC would compare the data submitted to AROC against the information contained in the facility's database and the corresponding (de-identified) medical record. A draft agenda for each visit is provided at Appendix 3.

Of the thirty facilities that were invited, three did not respond and were unable to be contacted, one facility had closed recently, and one facility cancelled at short notice after accepting due to staffing issues. The invitation was extended to two other facilities, which accepted at short notice. Several facilities rescheduled visits. Twenty seven facilities were visited in total.

The review process provided an opportunity to identify the key areas of need as they relate to the data collection process, data entry integrity, access to accurate medical records, data set knowledge and training to inform the development of an AROC Quality Assurance Plan.

The site visit also provided an opportunity to meet the objectives as specified in Activity 7 - Dataset and Data collection training, whereby a formal dataset/ data collection training

session was provided to staff, with a focus on the key issues highlighted during the review process.

7.4 Data Audit and Facility Visit

The overall impression gained from the audit was that the facilities were committed to collecting outcome data and wanted to use the resultant benchmarking reports to improve their clinical programs. There was a strong conflict in resource availability between clinical responsibilities and data collection priorities almost universally. Some facilities acknowledged the conflict and were actively seeking solutions or already working towards minimising the conflicts by incorporating the AROC data into team processes. Other facilities were floundering, with no identifiable staff members actively responsible for the data, and therefore, no-one in the rehabilitation team to champion the prioritisation of AROC data.

It was found that a number of factors affected the planned scope of the audit:

- The labour intensive nature of record audit
- Tight timeframe - one working day at each facility
- Staff resources at the facility
- Incomplete records
- Incorrect records being made available
- Sensitivity about confidentiality of records

As a result, in many cases a complete undertaking of both the data quality audit and the data set training and feedback session in a single facility visit was not possible. The number of record audits varied at each facility, depending on the individual circumstances in each service. Overall:

- Twenty seven facilities were visited, and 280 records audited
- AROC attempted to audit 1% of records
- There were some barriers to achieving this and only half of the records planned to be audited were actually audited
- Data issues were established from review of a very small number of records, and only confirmed by audit of a greater number of records
- Insights from facility staff greatly assisted in highlighting data issues and confirmed the findings of the audit
- Equal priority given to audit and local issue/ data set education

7.5 Data Issues Identified

There were varying issues identified at individual facilities, with some “clusters” of facilities experiencing similar issues within public or private health organisational structures.

Common issues identified in the audit:

- Incomplete data
- Use of redundant data set version
- Lack of understanding of data set resulting in systematic errors
- Small number of specific data items are commonly misunderstood, around time since onset, leave days, suspensions, discharge accommodation and level of support on discharge, co-morbidities and complications and dates of rehabilitation plan
- Lack of integration of data set collection in rehabilitation process and therefore documentation

- Lack of integration of outcome measurement
- Incorrect data entry
- Retrospective data collection resulting in poor quality data
- Lack of data set collection form
- Lack of supporting information in clinical record
- Incorrect data production in IT systems, eg incorrect auto-population of data
- Collection of data by non clinical staff resulting in poor quality data
- External responsibility for data submission
- Limited knowledge of how to utilise benchmarking report

7.6 Facility Audit Reports

Each facility has been provided with a comprehensive audit report. The report was sent to key clinical staff and also the key manager at each Facility. The report contained some common information, in addition to individual feedback about the data issues found. Recommendations were provided for the data issues identified. Along with the report a “AROC Resources” package was provided to each facility.

7.7 AROC Lessons

AROC acknowledges that although an existing website, “help desk service”, newsletter and regular contact around error reporting after data submission, is provided currently, the availability of more individualised assistance from AROC was universally welcomed by services. The availability of individual face to face support versus remote supportive resources to facilities experiencing challenges with data was invaluable. It is AROC’s aim to work towards providing these services on a more permanent basis to facilities collecting AROC data in the future, although funding will need to be found to support this. When the resources are made available, the significant improvement in data quality that is expected at the participating facilities will be able to be evaluated more fully.

AROC lessons in summary:

- Provision of ongoing individual facility support is a necessary resource
- Web based supporting documents are helpful to services, but should be backed up by other sources of information
- “AROC help desk” and error reporting post data submission are a vital services, however provision of ongoing individual facility support may result in greater improvement in data
- AROC’s profile through current avenues (website, written communication/ newsletter, reports, emails etc) is not as high at the grass roots level as desired

7.8 Quality Assurance Plan

The audit provided an invaluable opportunity to gain access to facilities and gain a high degree of clarity about data issues facing clinicians and support staff. All facilities acknowledge that an investment in developing an integrated and reliable data collection and reporting process was necessary. The investment resulted in a more accurate reflection of the activities of the facility, and was better than an ad hoc approach that was still resource intensive but was not clinically relevant.

The quality issues identified during the facility visit informed the development of an AROC Quality Assurance Plan (attached at Appendix 5), the key points of which are summarised here:

Completeness of data:

- Continued reminders to ensure completeness in benchmarking reports
- Support from AROC for services to assist with monitoring data

Accuracy of data provided to AROC:

- Provision of templates of forms for services
- Development of an AROC recommended data collection process (schematic)
- Recommendation to members to develop rehabilitation team processes and documentation that include AROC data collection and outcome measurement
- Development of “AROC Resources” information pack
- Data set education
- Recommendation to services to maintain an AROC resource folder for staff

Accuracy of data entry, coding and analysis:

- Continued liaison with services who use alternate IT collecting systems
- Continued development of a new web based reporting system with increased “user friendly” data quality checks
- Provision of supporting documents (AROC Resources information pack)
- Continued provision of automated error reports
- Continued liaison with facilities at the time of error reports

Timeliness of collection and reporting:

- Recommendation to members to collect data prospectively
- Encouragement and support to submit data locally
- Continued reminder and follow-up communication to facilities around data submission dates

8. Activity 7 – AROC Dataset/Data Collection Training

Principles 22-26 lay out the requirement for ensuring data quality, and suggests the provision of ongoing training for data collection and coding as one strategy to reduce errors in data.

In the past AROC has provided dataset and data collection training workshops in major centres around Australia, and have found them an extremely useful tool in ensuring the quality of the data received by AROC. Staff turnover in facilities, combined with the cost of training means that the opportunities for ‘grass roots’ staff to gain an in depth knowledge of AROC, the dataset, why items in the dataset have been included, and what the data they work so hard to collect is used for, is often very limited.

However, due to resource limitations we have not been able to provide dataset and data collection training at individual member’s facilities. As part of this project, and in conjunction with the Data Audit activity described above, AROC proposed to provide each of the audited AROC member facilities access to a visit from an AROC staff member, to provide dataset and data collection training, and to work with the facility to ensure their processes are such that the quality of the data they submit to AROC is as high as possible.

8.1 Data set Education During Facility Site Visits

An education session was provided at each facility during the site visit. The session was based on a presentation of the complete AROC data set, but was tailored to each facility and the areas of need that were identified during the audit. In many cases, staff members were able to identify their own areas of need, and were eager to clarify information, even prior to knowing the results of the audit.

Each facility identified the need for ongoing education about the data set, but in many cases had not sought assistance or sought to use already available resources. In some cases communication about AROC data set education sessions has not been reaching key staff in the past, or attending off site education was not possible due to staffing constraints. The value of the individualised data set education is further proof that facilities require, and significantly value, a face to face presence from AROC in support of their AROC data collection.

9. Activity 8 – Formalisation and Documentation of AROC Data Policy

Principles 19-21, 30-31 lay out the principles relating to data security and data access. Whilst AROC has had appropriate policies relating to the capture, housing, security, access, analysis and distribution of data, these policies have not been formalised or documented in a Data Policy manual. This activity has involved the review of the AROC data policies in line with the Operating Guidelines & Technical Standards, a review of other relevant data policy documents and then formalisation and documentation of the AROC policies into an AROC Data Policy document.

The draft AROC Data Policy is provided at Appendix 6. In association with the development of this policy, AROC also developed a Data Access Application Form and associated Guidelines. This document is provided at Appendix 7.

Both these documents are currently in draft form, as they require review and endorsement by the AROC Scientific and Clinical Advisory Committee. Once endorsed these documents will be published and made available to appropriate stakeholders and interested parties.

10. Discussion

Clinical registries can have a key role in monitoring and improving the quality and safety of Australian health care. As is understood by the Commission, they have the potential to provide a strong evidence base for determining the efficacy, safety and quality of providers, interventions, medications, devices and treatments.

Registries have been established based on varied reasons, but largely underpinned by a desire to improve quality and safety in the health care system. As evidenced by this current project, to date there is no single standard or shared methodology for the development, establishment and ongoing management of clinical quality registries.

The aim of the Australian Clinical Quality Registries project was the development and validation of a best practice model of operating principles and technical standards that would be applicable, useful and available to both new and existing registries.

As a well established registry AROC found it very useful to participate in this project and assess itself against the draft Operating Principles and Technical Standards. Pleasingly the assessment identified that AROC met the vast majority of the operating principles, and the relevant technical standards. For those it didn't currently meet the reasons were largely resource related, and participation in this project has allowed AROC to now meet those principles. Participation in the project also allowed AROC to learn more about the clinical registry landscape in Australia, and how AROC fits within that.

10.1 Role of Registries in Australia

As part of this final report AROC has been asked to comment on the role of registries in Australia and on whether a national registry strategy is a good idea. As stated above, clearly, and not surprisingly, AROC believes there is a clear role for clinical registries in Australia. The ultimate aim of the majority of registries is improving patient care and outcomes through greater understanding of events, treatments and outcomes. Most undertake this by collecting data describing a health care event, and then analysing, risk adjusting and casemix adjusting these data to provide participating providers/clinicians with information about their own practice compared with that of others. This information can (and does) drive quality improvement, thus having a significant impact on the provision of care, and (back to the ultimate aim) the quality of outcome for the patient.

Whilst the prime role of AROC was established to be data collection and benchmarking, as the registry has developed AROC has evolved to have a number of other roles:

- Facilitating the development of industry agreed outcome targets. As these are developed by the sector for the sector there is significant buy-in and thus utilization of these outcome targets
- As the volume of data in the database has grown, and given that AROC's coverage is national, AROC has become an access point for interested parties wanting to utilise analysis of the AROC data to support their rehabilitation related research
- AROC has become identified as a recognised industry expert and is sought as a key expert in the rehabilitation sector. AROC is available to provide evidence to support (or counter) claims made regarding outcomes or efficacy of rehabilitation, and to contribute to the development of policy that will affect the rehabilitation sector. AROC supports the discipline of rehabilitation, widely demonstrating the value of the data being collected, and the outcomes of AROC services.

- Given AROC's broad knowledge across the entire rehabilitation sector, AROC also plays a role as a networking facilitator. AROC can help members who have an issue identify appropriate contacts who may be able to help them solve that issue

10.2 National Registry Strategy

The development of a National Registry Strategy that elucidates the value of registries, provides an outline of the current Australian registry landscape, provides a suggested roadmap for development of further registries targeted at priority health areas and provides guidelines for registry development (through a document such as the Operating Principles and Technical Standards) is definitely a good idea. Given the Commission's work to date, they would be a logical entity to take the lead on the development of such a strategy.

The Commission could also play a role as the facilitator of networking between registries, and potentially as a key lobby point for registries seeking access to public funding. A note of caution here – the establishment of any competitive funding process (limited pie of dollars, so registries forced to compete) would have a detrimental affect on the evolution of high quality Clinical Quality registries in Australia. Registries value is in part because they act independently; control (in the form of funding) would be very damaging.

The extension of a National Registry Strategy to require 'accreditation' of registries is problematic – that way lies bears !! As stated previously the strength of registries is their basis in the coal face clinical provision of care, and the desire (not requirement) of clinicians to work towards providing a higher quality of care and outcomes for their patients. Guidance versus requiring compliance will be more effective. In addition, creating an accreditation requirement is establishing an additional layer of bureaucracy with all the associated cost of that, and as has been pointed out, registries already tend to work with limited resources. Meeting 'accreditation' costs would be diverting resources from the core purpose of the registry.

There is definitely the potential for some registries to join forces around the establishment and provision of 'back-end' type functions (IT systems, data storage, (supervised) data analysis, etc). However core functions such as member recruitment, relationship management, communication belong with individual registries who control the 'entanglement' of their particular registry with the stakeholders from their sector within the broader health care sector.

10.3 Suggested Enhancements to Operating Principles & Technical Standards

Many of AROC's suggestions for enhancements to the Operating Principles and Technical Standards are embedded in comments provided throughout this report.

In thinking through the key reasons for the success of AROC to date, a number of factors emerge, and AROC believes that the Operating Principles should probably encompass these factors in some way:

- Entanglement – since inception AROC has pursued a strategy of entanglement, working to ensure that AROC membership is necessary for all stakeholders within the rehabilitation sector. From an AROC perspective that has included such things as working very closely with AFRM (clinicians) even to the degree of education regarding AROC being part of an AFRM trainee's training, including the rehabilitation clinical indicators in the AROC dataset; ensuring active AROC membership is a requirement of public sector funding agreements and private sector funding contracts

- Visibility – AROC never loses an opportunity to present AROC data and demonstrate the value, usefulness and application of the data being collected
- Relationship Management – across all stakeholders, but most specifically with data submitting providers
- Demonstrate Value of AROC Membership – provision of benchmarking reports that are useful at a coal face, clinical level
- Diversified funding sources – both a positive and a negative. Operationally, collecting money from many sources is resource intensive, however it is also part of entanglement, and ensures all stakeholders have a bit of skin in the game. Diversified funding sources also give a level of protection to AROC in the event of a funder pulling out.

The operating principles may also be enhanced if some level of hierarchy of principles was established. It appears from those pilot sites that were establishing new registry that meeting all principles from inception of the registry was a big ask, and an enormous resource sink, often at a time when resources were limited. AROC, established now for some 7 years, did not meet all principles, but has been operating quite successfully. For example, a clear focus up front on establishing an appropriate governance structure, recruiting members, giving them the resources to begin data collection (even before an IT system is developed) and securing ongoing funding, would take precedence over developing a comprehensive suite of policies and sinking a lot of precious resources into an IT system that meets all the technical standards.

10.4 Next Steps for the Operating Principles & Technical Standards

Once the evaluation of the Clinical Registries project is complete and feedback from the project is incorporated into the Operating Principles & Technical Standards, AROC believes a strategy of education and dissemination of the document is required and appropriate. If this was undertaken, in part, as a series of registry workshops, such a strategy would also provide the potential to establish a registry networking group. In terms of further ahead, the comments above provide our thoughts on the role of registries in Australia and the potential for development of a national registry strategy. The Operating Principles & Technical Standards will play a key role in any such development.

Appendix 1 - AROC Clinical Data Set - Data Definitions and Guidelines

Australasian Rehabilitation Outcomes Centre (AROC)

Clinical Data Set - Data Definitions and Guidelines

Produced April 2009

1. Introduction

1.1 About AROC

The Australasian Rehabilitation Outcomes Centre (AROC) is a joint initiative of the Australasian rehabilitation sector (providers, funders, regulators and consumers). It commenced operation on 1 July, 2002. With the support of its industry partners, AROC has been established by the [Australasian Faculty of Rehabilitation Medicine \(AFRM\)](#). A business plan for AROC to run as a not-for-profit self-funding organisation was developed in early 2002 by an AROC Planning Group, consisting of representatives from across the sector.

AROC collects and reports on data from the specialist medical rehabilitation sector. To do this effectively, data must be collected reliably and consistently. To that end, this document provides AROC data users with definitions and guidelines for the collection and use of the AROC data items.

1.2 AROC Inpatient Clinical Data Set

AROC commenced data collection in July 2002 with Version 1 of the AROC Clinical Data Set. This version of the data set remained in use until September 2003 when the AROC Clinical Data Set Version 2 was implemented. All episodes of rehabilitation discharged from a participating rehabilitation facility up to and including June 2007 were submitted to AROC conforming to the Version 2 data specifications.

The Version 3 AROC Inpatient Clinical Data Set was implemented in July 2007. The Version 3 data set implementation was in line with the implementation of the AN-SNAP Classification Version 2, the release of the UDS Impairment Codes – Australian Version 1 and the release of the latest version of SNAPSHOT.

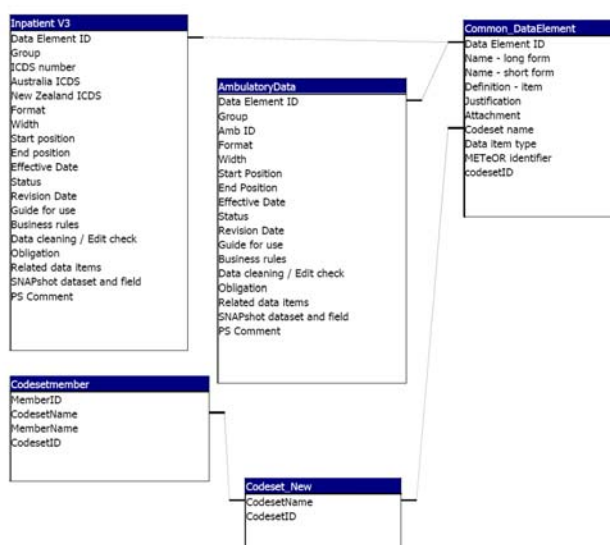
1.3 AROC Ambulatory Clinical Data Set

An original objective of AROC was expansion of data collection to the non-inpatient or ambulatory care setting after having established inpatient data collection and benchmarking. A draft data set was developed, piloted and refined during 2007/08 with the involvement of stakeholders through members of the AROC Scientific and Clinical Advisory Committee (SCAC).

The ambulatory data set (version 1) is based on the AROC Inpatient Clinical Data Set, modified to include items that relate specifically to evaluating the efficacy of ambulatory rehabilitation programs.

1.4 Database Schema for AROC Data Dictionary Development

The Database schema and Table descriptions for the AROC Data Dictionary are depicted below:



Tables Description

Table Name	Description
Common_DataElement	This table records all generic data elements appearing in all datasets, each data element has unique ID.
Inpatient V3	Includes all data elements in Inpatient version 3 dataset, each data element inherits attributes from "Common_DataElement" table and has its own attributes in inpatient dataset, such as "ICDS Number"
Ambulatory Data	Includes all data elements in Ambulatory Version 1 dataset, each data element inherits attributes from "Common_DataElement" table and has its own attributes in Ambulatory dataset, such as "Amb ID"
Codeset_New	Records all the codeset names with unique codeset ID, one generic data element could have no or one codeset.
Codesetmember	Records all the codeset members, one codeset could have no member or many members.

1.5 AROC definitions

1.5.1 Establishment

This is the entity that holds membership with AROC. It is usually the entity that is licensed by the relevant authorities to be a health care provider, and provided with an appropriate license or provider number. For example an Area Health Service or District Health Board is NOT the establishment, the hospital (e.g. Princess Alexandra; Burwood Hospital) is the appropriate member. Where a member has a number of campuses, or wards providing rehabilitation they should be identified at the Establishment Name data item as Member, Campus/Ward (e.g. Princess Alexandra, BIRU; Burwood Hospital, SIRU).

1.5.2 Rehabilitation Medicine – Inpatient and Ambulatory

Rehabilitation

Rehabilitation medicine is that part of the science of medicine involved with:

- the prevention and reduction of functional loss;
- the limitation of restrictions of activity and participation arising from impairments;
- the management of disability in physical, psychosocial and vocational dimensions, and improvement of function.

A rehabilitation medicine service aims to provide people with loss of function or ability due to injury or disease with the highest possible level of independence (physically, psychologically, socially and economically). This is achieved through a combined and coordinated use of medical, nursing and allied health professional skills. It involves individual assessment, treatment, regular review, discharge planning, community integration and follow up.

Inpatient rehabilitation

Inpatient rehabilitation is:

- rehabilitation delivered in an inpatient setting, with the patient accommodated overnight in the facility
- episode starts with a multidisciplinary assessment
- program of care designed around functional goals, short and long term
- program is time limited
- program of care is multidisciplinary

Ambulatory rehabilitation

Ambulatory rehabilitation is:

- rehabilitation delivered in an ambulatory setting, either centre based or in the community
- episode starts with a multidisciplinary assessment
- program of care designed around functional goals, short and long term
- program is time limited
- program of care is multidisciplinary, but therapies not necessarily delivered concurrently

Ambulatory rehabilitation can be either a continuation of an inpatient episode of rehabilitation into an ambulatory setting, or a rehabilitation program provided solely in an ambulatory setting.

Ambulatory rehabilitation is not someone visiting outpatients for physiotherapy on an ad hoc basis, or similar (not part of a planned rehabilitation episode).

1.5.3 Patient

Patient/person/client - To facilitate consistency in the language throughout this document please note the term patient/client/customer/consumer is referred to as patient; this is the person being treated for rehabilitation.

1.5.4 Episode (start/end) – Inpatient and Ambulatory

Episode start – Inpatient rehabilitation

Rehabilitation begins when:

- the patient is admitted to the rehabilitation unit; and/or
- the care type is changed to rehabilitation no matter where the patient is physically located (rehabilitation ward, acute ward, ICU); and/or
- the rehabilitation team forms part of a shared care arrangement (neurology specialist AND rehabilitation specialist) and the patient actively commences a rehabilitation program.

Episode End – Inpatient rehabilitation

Rehabilitation ends when:

- the patient is discharged from the rehabilitation unit; and/or
- the care type is changed from rehabilitation to either acute or some other form of sub-acute (maintenance/palliative care) no matter where the patient is physically located (rehabilitation ward, acute ward).

Episode Start – Ambulatory rehabilitation

Rehabilitation begins when:

- the patient is accepted into an ambulatory rehabilitation program; and
- the rehabilitation team undertakes an initial assessment; and/or
- the rehabilitation team actively commences providing rehabilitation therapies as part of a designed rehabilitation program

An ambulatory episode comprises a number of occasions of service. Each time a therapy is provided to the patient it is counted as an occasion of service; one therapy provider may provide an occasion of service to one or many patients at the same time (one to one therapy versus class based therapy).

A patient may receive a number of occasions of service on the same day (e.g. physiotherapy in the morning and speech pathology in the afternoon). Each day on which a patient receives one or more therapies is counted as a rehabilitation day.

In ambulatory rehabilitation days are not necessarily contiguous. A patient may have rehabilitation days two or three times a week for a number of weeks. Thus the count of time between episode start and episode end may (and is usually) many more days than the count of rehabilitation days.

Episode End – Ambulatory rehabilitation

Rehabilitation ends when:

- the patient is discharged from the ambulatory rehabilitation program; and/or
- the care type is changed from rehabilitation to either acute or some other form of sub-acute (maintenance/palliative care), either inpatient or ambulatory; or
- the patient does not come back for treatment; or
- the patient is discharged at their own risk.

2. AROC Clinical Data Set Metadata

Metadata is simply defined as “data about data”. The following metadata items define the Data Elements of the AROC Inpatient Clinical Data Set and AROC Ambulatory Clinical Data Set:

2.1 Data Element

The name of the item to be collected in the AROC ICDS. This is the same as the *Name - long form*. Refer also to *Name - short form*.

2.2 Data Element ID

Unique number allocated to each Data Element for management of items in the Data Elements database. This unique number also facilitates management of Data Elements between different releases of the Data Set and between different Data Sets collected by AROC.

2.3 Format

Type of data of the Data Element, for example, alphanumeric.

2.4 Width

Number of characters or digits in a fixed ASCII file for the Data Element.

2.5 Start position

Column in a fixed ASCII file that item begins in.

2.6 End position

Column in a fixed ASCII file that item ends in.

2.7 Group

Within the data dictionary, Group refers to whether the Data Element is part of a Data Element group or not. For instance the item AdmEat is one of 18 items that makes up the grouped Data Element *Episode start FIM scores (18 items)*. If the item is not grouped then it is referred to as "general".

2.8 Name – long form

The full (long) descriptor of the Data Element.

2.9 Name - short name

The abbreviated (short) name of the Data Element.

2.10 Codeset name

The name of the relevant codeset for coding of the item. User must refer to the named codeset for acceptable values. Values outside the specified range, or not included in the codeset will not be accepted.

2.11 Australia ICDS

Indicates (Y) whether the item is or was in the AROC Australian Inpatient Clinical Data Set. Status gives data item currency.

2.12 New Zealand ICDS

Indicates (Y) whether the item is or was in the AROC New Zealand Inpatient Clinical Data Set. Status gives data item currency.

2.13 Ambulatory CDS

Indicates (Y) whether the item is or was in the Ambulatory Clinical Data Set. Status gives data item currency.

2.14 Commencement date

The date the item was first made effective. This will correspond to AROC Version release dates: Version 1 - 1/7/2002, Version 2 – 1/9/2003 or Version 3 1/7/2007.

2.15 Status

Whether the item is Current or has been Deleted.

2.16 Revision Date

Date inserted if the item has been revised in any significant way since its Commencement date. This will correspond to AROC Version release dates: Version 2 – 1/9/2003 or Version 3 1/7/2007. Details of the type of revision are not recorded here, user will need to compare released data set versions to identify changes.

2.17 Definition – item

Description of the Data Element.

2.18 Justification

Reason/explanation as to why Data Element are necessary for collection.

2.19 Guide for use

Specific instruction, for AROC users, regarding the collection of the Data Element.

2.20 Business rules

Specific rules, for AROC users, which must be followed for correct collection of the Data Element.

2.21 Data cleaning / Edit check

Checks and edits which must be carried out by AROC data managers to ascertain the quality of the data collected. These reflect, to some extent, the users' Business Rules.

2.22 Attachment

Some Data Elements require the user to view attached information which defines or specifies values that may be used to complete the data collection.

2.23 Data item type

The Data Elements can be grouped into one of the following data item types: demographic, clinical, episode or outcome.

2.24 Obligation

Whether collection of the data item is:

1. Mandatory – must be collected
2. Optional – up to user or facility to decide relevance/usefulness of the item
3. Conditional – usually conditional on the value entered for another Data Element, for example, if the entry for *Total number of rehabilitation treatment suspension days during episode* was >0 days then *Number of rehabilitation treatment suspension occurrences* must be completed.

2.25 METeOR Identifier

If the Data Element meets the definition (exactly) of a METeOR item, then the METeOR Identifier is detailed.

2.26 Related data item

Other AROC Data Elements which relate to the current item being defined are listed.

2.27 SNAPshot screen/field

For SNAPshot users this is the name of the SNAPshot screen and field in which the data for the Data Element can be entered.

Appendix 2 – Data Audit letter of Invitation



AROC
Building 29
University of Wollongong NSW 2522
Phone: (02) 4221 4411
Fax: (02) 4221 4679

chsd.uow.edu.auaroc
Email: aroc@uow.edu.au

Sent by email

Dear

Invitation to Participate in AROC Data Quality Project

Your facility is a current member of AROC submitting a data against the AROC inpatient dataset for each rehabilitation patient admitted to your rehabilitation service.

AROC are offering assistance to a small group of AROC members to improve their data quality as part of a clinical quality registries project for the Australian Commission on Safety and Quality in Health Care. Data quality is a key issue for AROC, in part because the data collected forms the basis of the national rehabilitation benchmarking undertaken by AROC.

What AROC can offer as part of this project:

- An AROC team member will conduct a site visit, liaising with staff and becoming familiar with local data collection processes and issues.
- A data audit will be performed comparing data provided to AROC against the information contained in the data entry software system and the source records.
- A log will be kept against each record, detailing missing data, inconsistency in the data from the source material and the process issues associated.
- Recommendations may be offered in response to any system/process issues that arise with the aim of improving data quality.
- A data set/data collection training session will be held later in the day, tailored to the needs of your facility, based on the findings of the data audit and the gained knowledge about local process in data collection.

Participation in the project is voluntary, and any recommendations made during the audit and education sessions will be made with the aim of assisting with the relationship between AROC and the AROC member, and improving data quality. AROC will require access to 25 records, the Health Information Manager or delegate and the facility delegated AROC co-ordinator for approximately 5-6 hours on one mutually negotiated weekday. The afternoon education session will be available to any number of staff your facility nominates to attend.

The project will ultimately assist to inform the development of the AROC Quality Assurance Plan allowing the identification of themes in issues contingent with data integrity, quality and

the processes of data collection. However, importantly there are direct benefits to AROC members who chose to accept the invitation to participate in the project.

At this stage we would anticipate being in your area in the week commencing DATE, and have tentatively scheduled your facility for a visit on DAY, DATE. However, this is tentative and can be negotiated.

If you would like to participate in this project please let us know by return email to Jodie Tazelaar-Molinia at jodietm@uow.edu.au by the Wednesday 20 May 2009.

Kind regards,

Frances Simmonds
AROC Manager

Monique Berger
AROC Team Member

Jodie Tazelaar-Molinia
AROC Team Member

Appendix 3 – Site Visit Draft Agenda

Clinical Quality Registries Project

Australian Commission on Safety and Quality in Health Care

Activities 6&7 – Data Audit/ Dataset and Data Collection Training

Site Visit Plan

A member of the AROC team will perform a site visit to the target group facilities upon acceptance of an invitation to participate in the audit project.

Prior to the visit AROC will provide the facility with a list of randomly selected episodes from the reporting period under review so that the appropriate source records can be made available on the day.

The visit will comprise of two parts; Data Audit and Training.

Data Audit

The morning will be devoted to the comparison of the data provided to AROC against the information contained in the data entry software system and the source records. A log will be kept against each record, detailing missing data, inconsistency in the data from the source material and the process issues associated.

It is anticipated that the log will highlight any areas of need as they relate to knowledge and process in data collection and will inform the focus of the training session to be held later in the day.

The log details will also be used to inform the development of the AROC Quality Assurance Plan allowing the identification of themes in issues contingent with data integrity, quality and the processes of data collection.

Training

On completion of the audit an opportunity will be provided to discuss the findings and 'brainstorm' solutions to any issues arising from the data collection process.

Key staff involved in the data collection will participate in a training workshop, focussing on the items in the data collection, the process of data collection, ensuring data integrity and incorporating the results of the data collection into meaningful clinical resources.

Appendix 4 – AROC Data Dictionary – Data Elements

(see attached document)

Appendix 5 – AROC Quality Assurance Plan

(see attached document)

Appendix 6 – AROC Data Policy

(see attached document)

Appendix 7 – Data Access Application Form

(see attached document)