

National E-Health Transition Authority
Projects #1 to #4

Project Report:
Priority Event Summaries and
Code Sets, and Jurisdictional
Gap Analysis

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DOCUMENT CONTROL

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Associated Documents	
Title	Description
Priority Event Summaries and Code Sets, and Jurisdictional Gap Analysis	Final report for NEHTA Projects #1 to #4, and summary of jurisdictional analysis of clinical information requirements.
Index of NEHTA Specifications	Structured hierarchy of the priority data groups for use as an index.
Priority Event Summaries - Descriptions	For each of the event summaries identified as priorities for national standardisation, a description of the context, together with an indication of the clinical data groups that might be expected, and some indication of implementation considerations.
NEHTA Technical Specifications	Technical specification of the completed data groups using the NEHTA specification template (based on ISO/IEC 11179).
NEHTA Specification Template Reference Guide	User guide for the interpretation of NEHTA specifications. Defines and further clarifies the concepts in the NEHTA specification template.
NEHTA Specifications - Guide for Use	User guide to assist with the interpretation and use of NEHTA specifications by those involved in development, implementation or operation of systems.
NEHTA Specifications - Summarised Format	Extract of key elements from the NEHTA technical specifications that provide a high level view of content without the technical detail.
Draft NEHTA Specifications - Summarised Format	Provides a high level view of content for the draft data groups that are near completion.
Adverse Reaction and Alert Archetype Representations	Archetype representations of the Adverse Reaction and Alert data groups. Archetypes allow for direct use by software systems.

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1 INTRODUCTION

The main role of the NEHTA Clinical Data Standards group (CDS), formerly known as the Clinical Information Program (CIP), is to develop the clinical data specifications to facilitate the interchange and semantic interoperability of clinical information across the Australian health system. Specific 2004/05 work items undertaken by the CDS are:

- Project #1 List of priorities for electronic health record (EHR)/clinical event summaries. (Completed September 2004);
- Project #2 Data specifications for the EHR/clinical event summaries prioritised in Project #1;
- Project #3 Priorities for critical clinical code sets to be developed at a national level. (Completed December 2004); and
- Project #4 Clinical code set development as identified in Project #3.

This document represents the final report on Projects #2 and #4 and summarises for each the consultation and development processes, deliverables, and includes recommendations for NEHTA consideration.

The Project briefs are summarised below:

Project No. / Title:	#2 Develop the Prioritised Event Summaries
Required Outcome(s):	By 30 June 2005: National endorsement of data set specifications for the 12 EHR/clinical event summaries prioritised in Project #1.
Deliverable(s):	A set of technical specifications providing for each of the prioritised event summaries.
Scope Issues:	Scope of Community-based Health and Allied Health event summaries to be determined.
Methods:	Targeted consultation with clinicians and other health professionals, clinical informaticians and other health data experts, and projects and organisations currently engaged in clinical data set specification and implementation.

Project No. / Title:	#4 Develop the Prioritised Code Sets
Required Outcome(s):	By 30 June 2005: National endorsement of clinical code sets identified for development at a national level within the available time frame.
Deliverable(s):	Code set specifications providing, for feasible national code sets: <ul style="list-style-type: none"> ▪ Concept models; ▪ Value domains; ▪ Definitions and guides for use as appropriate; and ▪ Recommendations concerning the resource, infrastructure and governance requirements for ongoing maintenance of the national code sets.
Scope Issues:	Scope to be determined via Project #3.
Methods:	<ul style="list-style-type: none"> ▪ Targeted consultation with clinicians and other health professionals, clinical informaticians and other health data experts, and projects and organisations currently engaged in clinical code set specification and implementation; ▪ Assessment of the current status of clinical data sets in Australia and worldwide; ▪ Development of underpinning conceptual models; and ▪ Synthesis and iterative refinement of code set specifications.

A 'gap analysis' of clinical data needs for all jurisdictions (state and territory) against the CDS data specified to date, was also undertaken at the request of the NEHTA Advisory Committee (February 2005). The process and outcomes of the jurisdictional consultations is also reported in this document.

2 PROJECT #2 - PRIORITY EVENT SUMMARIES

2.1 Background

In September 2004, the NEHTA Clinical Data Standards group (CDS) identified 12 priority events following national consultations. These priorities were endorsed by the NEHTA Advisory Committee (NAC) and formed the basis of the NEHTA Project #2 work program.

These 12 priority events are:

- Initial Health Profile;
- Medical Consultation - General Practitioner;
- Medical Consultation - Specialist;
- Diagnostic Investigation - Imaging;
- Diagnostic Investigation - Pathology;
- Hospital Discharge - Inpatient;
- Hospital Discharge - Emergency;
- Pharmacy Provision;
- Community Based Health Consultation;
- Allied Health Consultation;
- Referral; and
- Event Notification (for example, admission to hospital).

The document **Priority Event Summary - Descriptions**, provides a description of each of these 12 event summary types, including an indication of possible data group content and implementation considerations. In February 2004, the CDS presented a list of data groups considered the most commonly required content across the 12 event summaries, and these were prioritised for development (through consultations) as shown in Table 1 below. Since then development of specifications has been progressed for those ranked High (1, 2 and 3) priority. This report presents the status of those data group specifications.

Data Group	Category / (Priority)
Alert	High (1)
Adverse Reaction	High (1)
Legal	High (1)
Problem/Diagnosis/Complication	High (1)
Reason for Presentation (<i>now Reason for Encounter</i>)	High (1)
Procedure/Treatment (<i>now Clinical Intervention</i>)	High (1)
Medication	High (1)
Clinical Synopsis	High (1)
Diagnostic Imaging	High (2)
Pathology Episode	High (2)
Immunisation	High (3)
Observation	High (3) based upon a small set of observations
Comprehensive Assessment (<i>now Standardised Comprehensive Assessment Procedure</i>)	Medium
Functional Status	Medium

Data Group	Category / (Priority)
Management Plan	Medium
Requested Service	Medium
Care Team	Medium
Lifestyle	Medium
Social Circumstance	Medium
Family Clinical History	Medium
Discharge	Medium

Table 1 - Prioritisation of data groups for development

2.2 Specification of Event Summaries - Generic Approach

The deliverable for NEHTA Project #2 is 'Data Specifications for the EHR/clinical event summaries'. The February NAC Status Report also identified a high degree of commonality in event summary content, that potentially each event summary could contain all or most of the identified data groups. Also, for any given event summary, the actual data that might be supplied can vary significantly. For this reason (with the endorsement of the NAC) the CDS has adopted a generic summary approach to specification. This is primarily a presentation issue with the individual event summaries now being packaged within a single product. Such an approach ensures clinical utility irrespective of the clinical scenario, and negates the need to predetermine and gain consensus on the data groups for each potential event summary. This approach should prevent the proliferation of different event summary constructs over time. It also has the advantage of flexibility and allows users to construct their event summary based on local needs but consistent with national standardised data groups. Ultimately it will be up to the clinician, in combination with her/his clinical information system and local practice/policy rules to determine which data should be provided in a given clinical context.

The deliverable for NEHTA Project #2 at the high level of event summary specification is presented in the form of a 'generic event summary' represented as a structured hierarchical representation of all developed data groups (**Index of NEHTA Specifications** document). The document provides a high level description of all potential data groups (developed to the stage of technical specification by the CDS) that could be included in any event summary. At this stage only the High priority data groups (from Table 1) are included (except for the Legal data group withdrawn for the reason explained in Section 2.7). The associated detailed technical specifications sit elsewhere (**NEHTA Technical Specifications** document). This approach allows for incremental expansion of the Index as more data groups are developed.

2.3 CDS Metamodel for Data Specification

The CDS metamodel is used to specify the overall structure of an event summary. In general, clinical information is organised hierarchically according to event summary, data group, data element and value domain. Figure 1 illustrates the relationships between the various metamodel components used in the CDS data specifications and examples.

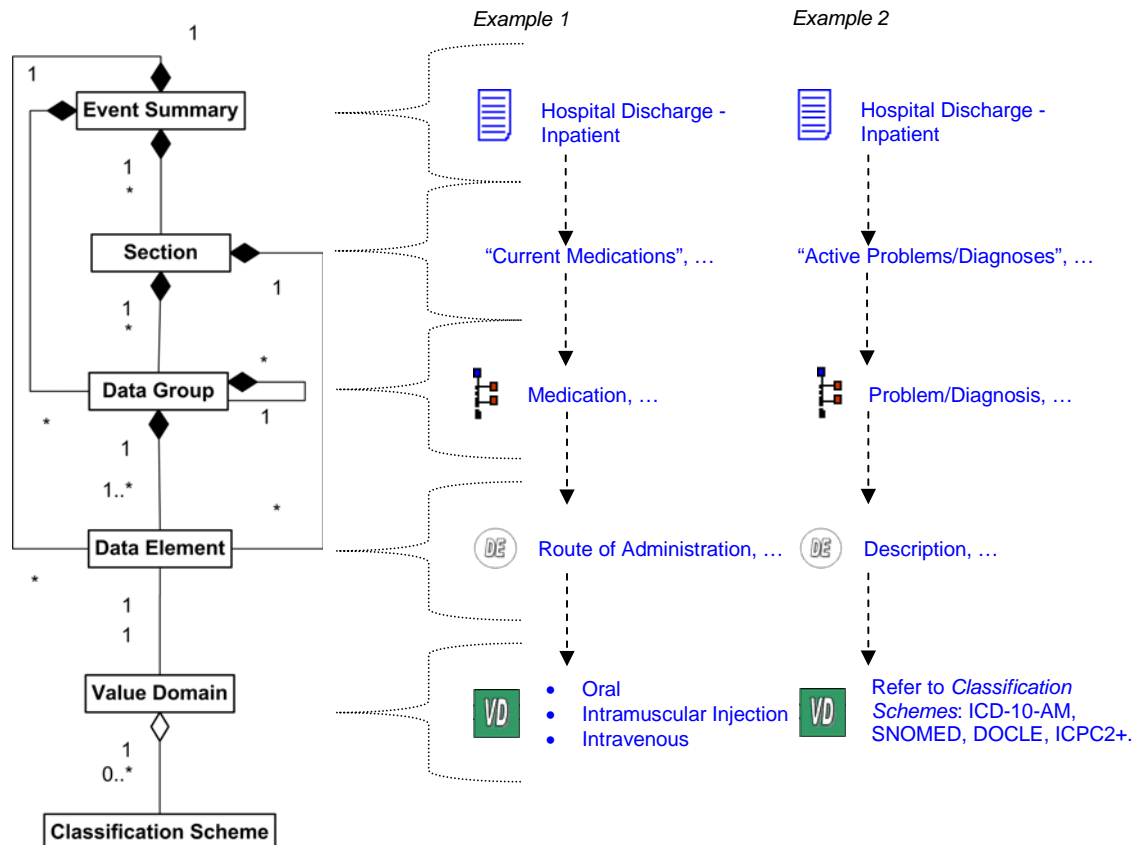


Figure 1 - High level metamodel and examples

2.4 NEHTA Clinical Data Specification Templates

The original format of the data specifications was based on the Australian Institute of Health and Welfare (AIHW) data specification template (using the ISO/IEC 11179 standard, 'Information Technology - Metadata Registries'). However, due to additional requirements for specifying clinical information, the CDS has defined the data specifications according to a redesigned metadata specification template - retaining the relevant attributes from the AIHW data specification template, and adding other required attributes.

The following key aspects are supported by the CDS data specification template:

- Application and implementation of independent specifications;
- Support for existing terminologies in value domains;
- Explicit definitions for metadata components;
- Support for reuse of components;
- Human-readable presentation;
- Specifying relationships; and
- Specifying data flows.

For further discussion on the concepts, format and language used in the CDS specifications, see the associated document [NEHTA Specification Template Reference Guide](#).

2.5 Deliverables

Data Group Specifications

Detailed technical specifications are complete for all the high priority data groups except the Legal data group, which was considered as requiring substantially more development time to resolve significant

outstanding issues. The remaining priority data groups are presented for endorsement as NEHTA specifications for implementation and field trialling. These are:

- Adverse Reaction;
- Alert;
- Clinical Synopsis;
- Immunisation;
- Observation;
- Reason for Encounter;
- Problem/Diagnosis; and
- Clinical Intervention.

National and international bodies, such as the National Information Standards Organization (NISO) and HL7, are likely to consider these specifications as Draft Specifications for Trial Use (DSTU). Following a suitable period for evaluation and comment the DSTUs would then be incorporated into a fully accredited version of a standard. The specifications are in the document **NEHTA Technical Specifications**. This is a large document (approx. 300 pages). An extract is provided as a separate document for the Adverse Reaction data group (**NEHTA Technical Specification (EXTRACT) - Adverse Reaction**) for viewing or printing out for reference. An accompanying document **NEHTA Specifications - Guide for Use** assists users in the interpretation and use of the NEHTA specifications.

For users requiring more information about data group content than is provided in the **Index of NEHTA Specifications**, but not requiring the level of detail in the technical specifications, a summarised format has been compiled which provides definitions and other key elements from the detailed technical specifications (**NEHTA Specifications - Summarised Format**).

Three further data groups are near completion as NEHTA specifications, and expected to be available progressively over the next three months. These are:

- Medication;
- Pathology Episode; and
- Diagnostic Imaging.

The presentation of the above sets of data groups as complete for release or near complete was endorsed by the CDS Clinical Reference Group (CRG) at the April 2004 workshop (see Section 2.7). These data groups are presented in the summarised format only in the document **Draft NEHTA Specifications - Summarised Format**.

2.6 Consultation Overview

The current consultation process relates to the period January 2005 to April 2005. Extensive consultation and collaboration with health specialists and clinicians around Australia over the past two years has not only informed the direction and content of the CDS work, but facilitates enthusiasm and readiness for the adoption of e-health across the health sector.

The data specifications were refined in a series of multidisciplinary and targeted consultations with representatives from all states and territories. Consultation included a series of face to face workshops:

- Multidisciplinary clinical workshops in SA, WA and Tas;
- Specialist workshop re: Pathology;
- Specialist workshop re: Radiology/Imaging; and
- A care management and referral workshop (involving home and community care service and planning personnel).

Distribution of specifications for comment was emailed through:

- Clinical colleges and peak organisations; and

- Specialised organisations e.g. for Immunisation - Australian Technical Advisory Group for Immunisation (ATAGI), National Centre for Immunisation Research and Surveillance of Vaccine Preventable Disease (NCIRS), Australian Childhood Immunisation Register (ACIR), Department of Health and Ageing (DoHA) Immunisation section.

A final stage of consultation and review was undertaken with a workshop of the multidisciplinary CRG (the same group who had reviewed all previous specifications) expanded to include representation from College and Peak Organisations, Community Health and Community Nursing.

College and Peak Organisations

The CDS has involved clinicians extensively in its data development work to date. Many of the clinicians participating in workshops and other activities have a strong interest in health informatics. The CDS is keen to retain involvement of these clinicians, but is also seeking to broaden the opportunities for consultation by disseminating draft specifications through Colleges and Peak Organisations for review. Formal requests were made to Colleges and Peak Organisations between October 2004 and February 2005, to nominate a representative as the point of contact within CDS. The nominated representatives were asked to:

- Disseminate data group specifications to their organisation's membership (or special interest groups and committees) for comment and review, to identify any critical omissions or errors which would prevent this specification being submitted to become a national standard;
- Coordinate and collate this feedback; and
- Attend a meeting of the CRG and College/Peak Organisation representatives to conduct a final review and revision of data groups.

Representatives were nominated by 17 College/Peak Organisations including:

- Royal Australian College of General Practitioners;
- Royal College of Nursing Australia*;
- Society of Hospital Pharmacists*;
- Emergency Department (represented through the National Emergency Department Project Advisory Committee);
- Royal Australian and New Zealand College of Anaesthetists;
- Royal College of Pathologists of Australasia;
- Pharmaceutical Society of Australia;
- Royal Australian College of Surgeons;
- Royal Australian and New Zealand College of Radiologists;
- Australian Divisions of General Practice;
- Australian Medical Association;
- Australian Nursing Federation;
- Aged Care Association Australia; and
- National Allied Health Classification Committee*.

* Three College nominees were already members of the CRG.

Representatives from all College and Peak Organisations contributed to the data specification and provided written feedback, participated in the specialist Radiology and Pathology workshops and/or attended the CRG workshop meeting on 21-22 April 2005.

Feedback indicated that the data group specifications were generally adequate with five exceptions where further work was required, i.e. Functional Status, Social Circumstance, Lifestyle Drug and Alcohol, Nutrition and Physical Activity.

Colleges and Peak Organisation representatives conveyed their support for the objectives of the NEHTA program and looked forward to further opportunity to contribute to product development. Respondents generally felt that the data items in the draft specifications were relevant and they would use them.

AIHW Technical Review

The CDS recognised early in the process of clinical data development the importance of links to the statistical development and governance structures, e.g. Health Data Standards Committee (HDSC), Statistical Information Management Committee (SIMC), and alignment to the National Health Data Dictionary (NHDD) wherever relevant national data standards already exist. With support from the Australian Government DoHA, the AIHW is working with the CDS to improve the consistency of metadata representations without compromising the utility of the metadata to its various audiences. The following are AIHW tasks:

- Provide technical metadata review of data specifications with an emphasis on identifying overlap or duplication with existing NHDD metadata items supporting mandated statistical collections, including National Minimum Data Sets (NMDSs) and any 'operations' (e.g. aggregation, mapping) that would be required to meet statistical reporting requirements;
- Identify and make recommendations on any changes or additions that would improve alignment between data collected at the point of care for clinical purposes and its downstream statistical use for policy and research; and
- Provide feedback to CDS on definitions, data group specifications, value domains and conditions for use (where they are provided).

This feedback has been progressively received and incorporated as appropriate.

2.7 Clinical Reference Group

The CRG comprises the 17 College and Peak Organisations nominees, three of whom were already CRG members, and 16 other clinicians involved in previous CRG meetings. The existing CRG members represented practicing General Practitioners (GPs), including GPs participating in *HealthConnect* and *MediConnect* trials and remote health services), specialists in psychiatry, obstetrics, emergency medicine, community nursing, allied health and a health informatics/consumer representative.

A workshop was held, 21-22 April 2005, to review and discuss the developments of data groups, data elements and value domains, with particular emphasis on the 'high priority' data groups. Twenty five clinicians attended, including 14 of the 17 College and Peak Organisations nominees - the three unable to attend, each forwarded written comments for consideration. In addition, the CDS Clinical Consultant (full-time staff member) provided assistance and guidance before, during and after the workshop.

Clinical Reference Group Outcomes

By the end of the two day workshop all data groups were endorsed as being a) Completed NEHTA Specifications, b) Draft NEHTA Specifications - Near Complete, or c) Drafts in Development. Detailed appraisal was given to the priority data groups in the format of five working groups led by CDS staff, followed by feedback and review sessions of the whole group.

The CRG noted that the data groups nominated as Completed NEHTA Specifications would benefit from exposure to clinical working environments and use cases, and recommended that these specifications be made broadly available immediately to explore gaps, cross impacts, implications and contingencies in aligning these developments with other initiatives. The need for management and governance mechanisms was also raised.

CRG Assessment of NEHTA Specifications

Of the priority data groups, the CRG supported the following data groups for release as NEHTA specifications:

- Adverse Reaction;
- Alert;

- Clinical Synopsis;
- Immunisation;
- Observation;
- Reason for Encounter;
- Problem/Diagnosis; and
- Clinical Intervention

For the data group Observation, it was recommended that archetypes, or something similar, should be considered for future development - it currently has a generic structure.

A further data group, Participant Identification was also endorsed. This group contains the data groups and data elements for client and healthcare provider identification as determined from the Australian Standards, AS 5017 'Health Care Client Identification' and AS4846 'Health Care Provider Identification'.

Draft NEHTA Specifications - Near Complete

Of the priority data groups, three were judged by the CRG as not yet suitable for release. The expectation is that a further two to three months refinement is necessary. This is a reflection of their complexity, and some concern about the difficulty in interpreting them in their current layout. The three data groups still considered Draft in Development by the CRG are Medication, Pathology Episode and Diagnostic Imaging, with the required work outlined below:

- Medication: Further analysis of medication systems to support compatibility and to confirm consistency with existing jurisdictional systems;
- Pathology Episode: Restructure of data groups around a pathology episode; and
- Diagnostic Imaging: Restructure of data groups around an imaging episode. Further consultation required with key stakeholders and alignment with draft Australian Standard.

Draft NEHTA Specifications - In Development

Of the priority data groups considered by the CRG, the Legal data group was considered as requiring considerably more development. Their primary concern was the differing legal requirements and terminologies used in jurisdictions, and it was suggested that a targeted, rather than generic, approach to data elements and value domain content is necessary. It was also recommended that consumer and legal groups need to be involved. It was suggested that as an interim measure, the Legal terms contained in the Alert value domain should stay in that domain and be publicly available for comment.

All other data groups, that is, the 'medium' priority groups in Table 1 above were also included in this category. The CDS has commenced development of these in preparation for targeted consultation:

- Care Team;
- Current Service;
- Family Clinical History;
- Management Plan;
- Requested Service;
- Clinical Context;
- Lifestyle;
- Standardised Comprehensive Assessment Procedure;
- Discharge;
- Functional Status;
- Social Circumstance; and
- Social Demographics.

Given the number of groups a prioritisation process is necessary. (Note - the Jurisdictional Analysis of Clinical Information Requirements will inform priorities - see Section 4)

3 PROJECT #4 - CLINICAL CODE SET DEVELOPMENTS

3.1 Overview

In December 2004, the Australian Health Ministers Advisory Council (AHMAC) Working Group endorsed Adverse Reaction and Alert as the two critical clinical code sets (value domains) for initial national development. The CDS contracted the National Centre for Classification in Health (NCCH) to undertake the value domain developments between December 2004 and April 2005.

3.2 Adverse Reaction and Alert Value Domain Development

The value domains for Adverse Reaction excludes drugs pending the provision of an accepted medicines terminology. The Australian Medicines and Devices Terminology (AMDT) project has primary responsibility for developing a standard national drug terminology. There has been a reluctance to duplicate efforts or to undertake (potentially) contradictory developments, and confuse the terminology and semantic interoperability landscape with multiple choices. The work being undertaken by both the AMDT project and the CDS value domain project has meant that the NCCH has been unable to comprehensively develop the value domains that are reliant on an agreed drug terminology. It is hoped that the AMDT development will provide a medicines terminology that encapsulates various levels of specificity and shares hierarchical and navigational properties, e.g. therapeutic class, generics, brand names, combinations, dosages, etc, consistent with the multi-axial, concept-oriented approach of most terminologies under consideration. Further value domain post-processing and re-development will be necessary when the AMDT is available.

Design and Methodology

The designs and methods adopted provide for flexibility and adaptability, incorporate existing code sets and systems and allow for migration to other emerging standards. It must be highlighted that it is possible that low frequency, rare clinical events may not appear in this foundational data.

In essence, value domain content for Adverse Reaction and Alert comprises approximately 3,000 relevant terms. The development approach incorporates:

- Top-down development - incorporates appropriate top-down ordering principles and high level concepts. Used the CDS draft specifications as well as consideration for existing terminologies and classifications to inform value domain content. Tractable to upstream data uses;
- Bottom-up development - accounts for legacy terms in clinical use. Harvesting concepts and terms from existing users and existing systems provided empirical evidence of value domain content requirements. Source terms were often 'dirty data' comprising free text entries, sometimes non-unique terms and concepts, often in flat file (list) format and contained shortened keyword abbreviations or alphabetic code sets (reflective of clinical user input); and
- Lateral development - harmonisation of content to form a superset that will serve as a national maximum terminology suited to specific use cases, subsets, views and further specification and deployment. Incorporated expert clinical advice and assessment deemed to be of great importance to value domain content development.

The newly developed content for Adverse Reaction and Alert was also compared with other terminologies, classifications and value domains to ascertain whether the developments aligned, were congruent and mappable to other recognised (or familiar) terminologies. Mapping is essential to Systematised Nomenclature of Medicine - Clinical Terminology (SNOMED CT) content, as well as other classifications that have broad international use or a national mandate.

Consultation

The focus of the work is entirely clinical and the key goal and intention of the terminology is to serve clinical communicative and clinical care requirements. Clinical consultations, where possible were held in conjunction with the CDS workshops for Project #2.

Valuable empirical information was obtained through a series of consultations with state health jurisdictions and clinicians. Personnel involved in managing or developing clinical information systems from Queensland Health's Clinical Information System Program (CISP), NSW Health's Point of Care Clinical Information System (PoCCS), and SA Health's Open Architecture Clinical Information System (OACIS). The Tasmanian Department of Health and Human Services and Austin Health in Victoria were involved in this consultative process. Consultation was extended to include collaborative workshops with groups of clinicians in Tasmania, Victoria, South Australia and Western Australia. Participants included GPs, surgeons, medical specialists, pharmacists, community and allied health specialists, dentists, nurses and pathologists. Web based consultation and review mechanisms were established to allow broader access.

Legacy Code sets and Data

Developments have incorporated terms and concepts used in existing systems, sometimes as terms, and sometimes as semantic relationships, e.g. synonyms, grammatical variants. In most cases, terms from existing systems have been mapped to the new value domain content, providing linkages between existing and emerging value domain content.

Migration and Future Proofing

Contiguous with the Adverse Reaction and Alert developments, Australia has been considering the need for a national standard clinical terminology which could provide terms and concepts for value domain content, for any (or all) data elements, proposed or potentially needed for a wide range of e-health initiatives. SNOMED CT has been identified internationally as the most likely candidate terminology, and an examination of its content, and the goodness of fit, is the subject of other studies and projects. It is possible that these outcomes could influence the value domain content developed through this project.

Mappings of the newly developed Adverse Reaction and Alert value domains showed promising results, and indicate adherence to best practice guidelines for terminology developments. Hence, the value domains have congruent terms and demonstrate semantic interoperability with SNOMED CT.

Development Results

The Adverse Reaction and Alert value domains will evolve over time and processes need to be defined for ongoing development, including maintenance requirements for clinical currency and alignment with emerging needs.

Data Group Data Element	Value Domain characteristics		
	Number of nodes* and terms**		Semantic relationships***
	No. of nodes	No. of terms	
Adverse Reaction			
Agent Type	1	7	0
Agent Description	6	1741	140
Adverse Reaction Type	1	24	4
Adverse Reaction Description	24	880	290
Alert			
Alert Type	1	9	7
Alerts Description	10	341	110

Table 2 - Value Domain details for alert data elements (cumulative results)

* refers to nodes at the top level of the hierarchy. Depth (and levels of hierarchy) vary considerably between data elements, and within child concepts of the same top level node.

** refers to the number of unique terms, though these each may hold several positions within a terminology (multi-parented; but counted here only once).

*** refers to the number of duplicates and variations for one term harvested from existing systems.

General Issues

- Many jurisdictions, and indeed many existing clinical information systems, have limited functionality and capability to implement the proposed (and perhaps ideal) data groups, data elements and value domains. While developments can be future-proofed to some extent, a staged implementation may be necessary;
- A risk associated with developing and implementing new specifications for value domains is that existing classifications, code sets and term sets will be superseded or replaced. This has implications for the use and persistence of existing data collections and health records which have utilised these classifications or code sets, thus breaking the continuity and comparability of clinical information; and
- The Adverse Reaction and Alert value domains have incorporated terms and concepts used in existing systems, sometimes as terms, and sometimes as semantic relationships (synonyms, grammatical variants). In most cases, terms from existing systems have been mapped to the new value domain content, providing linkages between existing and emerging value domain content.

Deliverables

The key deliverables for Project #4 are the value domains for the Adverse Reaction and Alert data groups. The document **NEHTA Value Domains for Adverse Reaction and Alert** is an extract of the value domain terms only (without the associated concepts and semantic relationships). It should be noted that this was extracted prior to 'cleaning' ready for final release at the end of May.

Following AHMAC Working Group (AWG) approval to release, the value domains can be provided in electronic format suited for browsing, incorporation into archetypes or clinical trials, as well as other formats as negotiated. A web-based version will also be released which contains all terms, concepts, semantic relationships and mapping information, including value domain content, hierarchies, synonyms, and relationships with existing code sets and classifications. Definitional information relevant to the data elements is also available.

3.4 Clinical Reference Group Outcomes

The CRG workshop 21-22 April 2005, included the review of the Adverse Reaction and Alert data groups and examination of the value domain content.

CRG Discussion

It was noted that the development of value domains (the terms used to populate the values of a data element) is iterative, and developments will be accelerated by early adoption and focused implementation. Substantial engagement with consumer groups and vendors is considered an essential step in supporting continued developments toward an agreed national standard. The release of the NEHTA value domain specification is the first step in this process.

The CRG acknowledged that the developments do not represent a definitive value domain for adverse reactions. This is because a meaningful value domain for adverse drug reactions will rely on links and relationships with an agreed medicines terminology (under consideration from the AMDT project). However, the CRG endorsed the release of the Adverse Reaction and Alert value domains in the current format. Further delays came with the risk that numerous local (uncontrolled) developments would escalate to meet demand, resulting in further difficulties in later re-alignments to an agreed standard.

The need for defining a governance cycle was identified, including a plan which will allow for a regular and responsive cycle of value domain additions, enhancements and refinements.

The CRG supports the development process; it is reasonable, sustainable and:

- Supports early adopters and vendors;
- Will provide 'first cut' value domains;
- Informs real world implementation;

- Provides evidence for iterative development;
- Is consistent with change rate of medical terminology;
- Reflects 'best practice' terminology building;
- Is in line with accepted standards development cycles; and
- Allows for clinical involvement and participation.

CRG Recommendation

The Adverse Reaction and Alert value domains be made available immediately as a 'first cut' and will benefit from broader consultation, exposure to clinical working environments and use cases.

4 JURISDICTIONAL ANALYSIS OF CLINICAL INFORMATION REQUIREMENTS

4.1 Background

This report follows on from the CDS work reported as part of NEHTA Project #1 completed in September 2004 and a status report on Project #2 presented at the February 2005 NAC meeting. Project #1 outlined priority event summaries and the status report 2 outlined the potential data content of those event summaries. A recommendation from the February 2005 NAC meeting was to map that data content against jurisdictional clinical data requirements to determine whether all jurisdictional priorities were covered, i.e. conduct a gap analysis and to determine next set of priorities for the CDS work program.

This document summarises the approach and outcomes of this gap analysis.

4.2 Approach

All States and Territories were included in the analysis, with meetings and workshops at the jurisdiction, except for NT which was conducted by teleconference. Jurisdictions were sent a set of worksheets prior to the visits listing all data groups and data elements currently being worked on by NEHTA. Workshops comprised the Chief Information Officer (CIO) and/or senior staff, representing a range of areas, including Clinical Information Systems, Community Health, Acute Care, Primary Care Integration, Aged Care, Chronic Disease, Mental Health, Public Health Surveillance & Registries (Immunisation, Communicable Disease, Cancer, Perinatal, Injury), Data Quality and Standards. Discussions were held separately with the CIO if not at the workshop. The stated aim of the meetings/workshops was to:

1. Identify the match/gaps between jurisdictional data collected (currently/planned) and current NEHTA data specifications;
2. Determine next code set priorities for NEHTA; and
3. Discuss jurisdiction view on NEHTA Clinical Data Standards work program and priorities.
 - Clinical areas / Event Summaries;
 - Data Groups; and
 - Data Elements/Value Domains.

During the workshops the method and timing for the gap analysis was decided (Item 1) and discussions held about potential priorities at the broad level (Items 2 & 3). It should be noted that no dedicated scribe was available at the workshops, hence it is possible that not all significant requests were documented. The worksheets provided further clarification of priorities and greater detail, including information on whether the information was captured (current or planned), in which systems and what format, e.g. free text, locally developed code sets. Appendix A shows a sample page from the worksheets.

A common complaint of the jurisdictions was the short timeframe in which to complete the worksheets. The exercise was seen as important, but needed to be fitted in with other NEHTA requests being made concurrently. ACT was the last jurisdiction visited and was unable to complete worksheets in time for this analysis. Due to time constraints, the worksheets for some other jurisdictions did not cover all the systems or clinical areas considered relevant and/or were not completed for all data groups (as the relevant person(s) could not complete the task in time); for example, one state was only able to provide an 'acute care' perspective, and in another state worksheets from regional service were used as a proxy. However, all states and territories contributed at the broad level (workshops/meeting) whilst the contributions at the detailed level varied. Nevertheless, the current outcomes need to be interpreted as incomplete and possibly not reflecting all jurisdictional needs.

It should be noted that the requirements for HealthConnect were evaluated as part of the jurisdictional analysis.

4.3 Findings

4.3.1 Clinical Areas / Event Summaries

The NEHTA Project #1 completed in September 2004 identified 12 priority event summaries as listed in section 2.1. As outlined in 2.2, the focus of CDS developments are on the data groups so that any event summary can be dynamically allocated/selected in line with clinical preferences at the point of care. There was general consensus with this approach by the jurisdictions during this round of consultations, with exceptions, and these exceptions would be determined as the need arose. The exceptions specified for priority development during these jurisdictional consultations were Discharge Summary (first and urgent priority) and Referral.

4.3.2 Outcome of Jurisdictional Workshops / Meetings

National (minimum) Discharge Summary Template

Of the 12 priority event summary types that have been identified by the CDS, a standardised Hospital Discharge Summary is of particular interest for the following reasons:

- Widespread demand for discharge summaries by GPs and community care services;
- A recognition for the need to standardise the content of discharge summaries;
- The current development activity being repeated across the nation to implement and streamline discharge summary generation and promulgation; and
- The fact that discharge summaries can contain the full spectrum of health information pertaining to a given subject of care.

Jurisdictions supported the finalisation of a national (minimum) Discharge Summary template to cover core discharge requirements as the immediate priority, with add-on modules developed for specialty-specific information in a priority order yet to be determined. It was also recommended that the specification be expressed as a standardised message to ensure uniform application. NEHTA is close to finalising a proposed specification of the Discharge Summary for consultation, and it is recommended that priority be given to this work within the next two to three months.

Appendix B shows a draft template with the core data groups common to sourced summaries from around the country and through consultations (primarily with GPs). The precise content of the data groups (data elements) needs to be finalised and concurrently aligned and mapped to the emerging AS4700.6 (Implementation of Health Level Seven (HL7) version 2.4 Part 6: Referral & Discharge Summary).

National Referral Template

A number of health jurisdictions have electronic referral initiatives, including:

- The Victorian Service Coordination Tool Templates (SCTT) initiative;
- The Queensland Ongoing Needs Identification (ONI) program; and
- The South Australian Initial Needs Identification tools (INI).

The Queensland and South Australian initiatives are derivatives of SCTT with a high degree of commonality.

A two day workshop, 31 March - 1 April 2005, was held that included representatives of these initiatives, as well as representatives from each of the jurisdictions except Northern Territory (due to other commitments). The workshop was extended to incorporate Care Management, given the high degree of association and included interests such as Home and Community Care. The workshop objectives were to review the applicability of current CDS priority data groups to Referral and Care Management, discuss critical data group requirements for Referral and Care Management, and commence development of content of critical data groups for Referral and Care Management ensuring support for current care transfer and management tools such as SCTT and ONI.

The outcomes of this workshop will inform further development and progress towards a national referral template. Given the many different contexts in which Referral is used, a period of review is required to determine the scope of Referral and establish whether a common template is feasible or a modular approach more appropriate to support different use contexts.

Clinical Areas

Apart from further development of these two event summaries (Discharge and Referral), it was agreed that the further development of the current priority data groups and determination of the next set of priority groups would be facilitated by focusing on priority areas of healthcare provision. For example the content (data elements required) from the Standardised Comprehensive Assessment Procedure data group is likely to differ for aged care versus mental health or paediatrics. NEHTA specification templates allow items from relevant data groups to be assembled into a hierarchical structure to support specialised information requirements in areas such as mental health or paediatrics.

From the jurisdictional workshops the following areas were nominated as priorities, in order of the number of jurisdictions nominating the area (shown in brackets). There may be additional areas in jurisdictional strategic plans that were not specifically mentioned at the workshops. Hence, jurisdictions need to review this list and provide advice as whether it truly reflects needs. The following are areas nominated by three or more jurisdictions as priorities:

1. Mental Health (6);
2. Aged Care (7);
3. Chronic Disease Management (4);
4. Community Health (4);
5. Maternity/Child (4); and
6. National (and state) priority Areas (3).

Others nominated were Notification, Coordinated Shared Care, Regional/Remote Care, Medication Management, Drug & Alcohol Services, Disability Services, Complementary & Alternative Therapies, Patient Record, Public Health/Health Promotion, Patient Transfer, e.g. Ambulance; Disaster Management, Micro Alerts, and Emergency Care.

4.3.3 Outcome of Jurisdictional Data Mapping (worksheets)

The worksheets applied only at the data group and data element level.

4.4 Data Groups

Table 1 (section 2.1) lists the data groups included in the NEHTA program by priority order for development.

4.4.1 Outcome of Jurisdictional Workshops / Meetings

NEHTA has been working primarily on determining the data element content of the high priority data groups (1, 2 and 3). During the current round of consultations, jurisdictions mostly supported these as the first set of priority areas, and at the workshops were asked to nominate data groups from the 'medium' list which were considered the next set of high priorities for development and also any others not listed that are priorities for the jurisdiction. From the workshops the following were nominated by three or more:

1. Comprehensive Assessment (5);
2. Management Plan (5);
3. Requested Service (4);
4. Functional Status (3); and
5. Adverse Event (3).

Data groups 1-4 are from the current list whereas 'Adverse Event' is a new data group. Adverse Events have been specifically excluded from the scope of the current development of the Adverse Reaction and Alerts data groups. Other data groups from the medium category were mentioned as priorities by 1 or 2 jurisdictions, whilst other new ones stated were maternity/babies, triage category, dental, genetic data, and complications.

4.4.2 Outcome of Jurisdictional Data Mapping (worksheets)

The worksheets related to all data groups. Data groups from Alert to Pathology in Table 3 (below), were reported as being included in most current jurisdictions, in at least one key system in some format (often free text or locally developed code sets). The others were variably reported as available in current systems.

Prioritisation of the data groups from the worksheets is summarised in the table below. The central column shows the number of jurisdictions ranking the data group as priority 1 (required within the next 12 months). The priority rating used was as follows:

0. Not required;
1. Required within next 12 months;
2. Required 1-2 years; and
3. Required > 2 years.

Data Group	Commonly included in current systems	Number of jurisdictions rating as priority 1.	Total jurisdictions responding to section
Alert	✓	6	7
Adverse Reaction	✓	6	7
Legal	✓	4	7
Problem/Diagnosis	✓	6	7
Reason for Encounter	✓	7	7
Clinical Intervention	✓	5	6
Medication	✓	7	7
Clinical Synopsis/Comment	✓	6	7
Diagnostic Imaging	✓	7	7
Pathology Episode	✓	7	7
Immunisation		3	6
Observation		2	6
Standardised Comprehensive Assessment Procedure		3	4
Functional Status		6	7
Management Plan		4	7
Requested Service		5	7
Care Team		3	4
Lifestyle (drug/alcohol, tobacco, nutrition, physical activity)		2,2,1,0	7,7,5,5
Social Circumstances		4	7
Family Clinical History		2	6
Discharge	✓	5	6

Table 3 - Prioritisation of data groups by Jurisdictions

These results are in concordance with the High priority (1) and (2) data groups (Alert to Pathology) in Table 1 (determined from prior consultations). The lower priority assigned to Immunisation and Observation aligns with these being assigned High Priority (3) previously on the basis that they are required for specialised purposes or on a partial basis, e.g. only some Observations being high priorities.

For the remaining data groups the following received a Priority one, by three or more jurisdictions:

1. Comprehensive Assessment (3);
2. Management Plan (4);
3. Requested Service (5);
4. Functional Status (6);
5. Care Team (3);
6. Social Circumstances (4); and
7. Discharge (5).

The first four match those from the workshops. It is possible that there may have been confusion about Discharge as an event summary versus a data group. The worksheets included feedback from people representing clinical areas unable to attend the workshops.

4.5 Data Elements/Value Domains

At the workshops the detailed data element content was not generally discussed except in relation to recommendations for value domain development. NEHTA Project #3 is about identifying priorities for national codeset development. In December 2004 two data groups were identified and endorsed by NAC, namely Adverse Reaction and Alert which NEHTA has been developing over the last four months. During these consultations, jurisdictions were asked to nominate the next priorities for code set development both during the workshops and in the worksheets.

It should be noted that although the term 'code set' was specified in the NEHTA work program, the work is better described as "value domain" development.

4.5.1 Outcome of Jurisdictional Workshops / Meetings

From the workshops there was almost complete consensus agreement on the priorities for value domain development for the top four listed below. It is envisaged that Medications is probably a high (if not the top) priority for all jurisdictions, but it was not specifically mentioned given the other known related NEHTA projects, e.g. Medications Formulary.

1. Reason for Encounter (6);
2. Problem/Diagnosis (6);
3. Clinical Intervention (6);
4. Diagnostic investigations - Imaging & Pathology (5);
5. Medications (3); and
6. Management/Care Plan (1).

4.5.2 Outcome of Jurisdictional Data Mapping (worksheets)

Data Element

There was significant variability in the inclusion of data elements in current systems. However, overall there is a high level of support for the data element content put forward by NEHTA for the existing priority groups. For example, out of six jurisdictions responding to the Alert data elements, all were ranked as priority one by four or more. Similarly three or more ranked the Adverse Reaction data elements as priority one. Support for the data element content of other data groups is more varied, however it should be noted that the existing medium priority data groups are at an early stage of development.

Value Domain

Table 4 (below) shows the data groups which contained recommendations for priority (rank 1) value domain development of at least one of the contained data elements by three or more jurisdictions. This reflects support for national development and desired consensus for common value domains and code sets for a significant set of data elements. As indicated above, the worksheets were incomplete especially for some data groups where jurisdictions did not have time to gain input from the relevant contact(s). Nevertheless these items were ranked as priority one by at least three jurisdictions, sometimes for items within data groups completed by only three or four jurisdictions.

Table 4 (below) suggests that in addition to the data groups nominated during the workshops for value domain development, additional priority groups are Diagnostic Imaging, Pathology Episode, Immunisation, Requested Service, and Discharge.

Data Group	Data Elements for which code set development recommended as Priority 1 by three or more jurisdictions
Alert	i) Type* ii) Description* iii) Status
Adverse Reaction	i) Presence ii) Type* iii) Description* iv) Severity v) Status vi) Certainty
Problem/Diagnosis	i) Type ii) Description iii) Status
Reason for Encounter	i) Description
Clinical Intervention	i) Description ii) Significance
Medication	i) Administering device ii) Administering method iii) Providers instructions iv) Adverse event v) Type vi) Frequency vii) Duration viii) Route ix) Product generic name x) Product brand name
Diagnostic Imaging <i>Note: items on worksheets at very preliminary stage</i>	i) Procedure performed
Pathology Episode <i>Note: these results are taken from an early version which has since changed significantly (incorporating this & CRG feedback)</i>	i) Specimen collection location ii) Laboratory iii) Lab request ID iv) Specimen ID v) Specimen type vi) Primary Anatomical Site vii) Secondary Anatomical Site viii) Specimen Characteristics ix) Quality of Specimen x) Requested tests Completed xi) Pathology tests xii) Test details

Data Group	Data Elements for which code set development recommended as Priority 1 by three or more jurisdictions
Immunisation	i) Vaccine Antigen ii) Injection site iii) Route
Requested Service	i) Referral service type ii) Referral source iii) Referral reason iv) Subject of care consent
Discharge	i) Summary purpose ii) Discharge reason & destination

Table 4 - Priorities for value domain development by Jurisdictions
* in current program for NEHTA code set development

4.6 Recommendations from Jurisdictional Analysis

Broad Clinical Areas

Two streams of work need to be supported.

1. To finalise priority event summary templates in the following priority order:
 - i) Discharge Summary; and
 - ii) Referral.
2. To further develop priority data groups (existing groups and those arising from current round of consultations) by focusing on clinical areas in the following priority order:
 - i) Aged Care, Chronic Disease Management & Community Care;
 - ii) Mental Health; and
 - iii) Maternity/child.

Data Groups

1. Development must continue for the existing priority data groups; and
2. Concurrently, additional data groups need to be incorporated into the work program in following priority order (related sets of data):
 - i) Management Plan, Requested Service, Discharge;
 - ii) Comprehensive Assessment, Functional Status, Care Team;
 - iii) Social Circumstances; and
 - iv) Adverse Event.

Data Elements/Value Domains

Value domain development focus is required on the following data groups:

1. Medications;
2. Diagnostic Imaging & Pathology Episode;
3. Reason for Encounter;
4. Problem/Diagnosis;
5. Requested Service & Discharge;
6. Clinical Intervention; and

7. Immunisation.

The first six groups appear to have more or less equal weight from the worksheets. It is suggested these be developed in the order listed, based on discussions from the jurisdictional workshops and other clinical meetings. Development of value domains for Medications will need to align with other NEHTA projects and standards work nationally.

5 OVERALL RECOMENDATIONS

The following recommendations draw together the work of NEHTA Projects #2 and #4 and the Jurisdictional Gap Analysis.

Recommendation 1

Specifications for the following data groups be released as NEHTA specifications ready for user implementation and field trialling:

- Adverse Reaction;
- Alert;
- Clinical Synopsis;
- Immunisation;
- Observation;
- Reason for Encounter;
- Problem/Diagnosis; and
- Clinical Intervention.

Recommendation 2

The Adverse Reaction and Alert value domains be made available immediately as a 'first cut' ready for user implementation and field trialling.

Recommendation 3

The following recommendations and priorities be endorsed for the CDS 2005/06 work program (Indication timelines are shown in brackets).

A. Broad Clinical Areas

1. Work must proceed in finalising two priority event summary templates in the following priority order:
 - i) Discharge Summary (end of September 2005); and
 - ii) Referral (December 2005).
2. Further development of priority data groups (existing groups and those arising from current round of consultations) proceed by focusing on clinical areas in the following priority order:
 - i) Aged Care, Chronic Disease Management & Community Care (over whole period);
 - ii) Mental Health (from January 2006); and
 - iii) Maternity/child (from March 2006).

B. Data Groups

1. That development continue for the existing priority data groups throughout the period when focusing on the various clinical areas.
2. Concurrently, that additional data groups be incorporated into the work program in the following priority order of related data sets:
 - i) Management Plan, Requested Service, Discharge (from July 2005);
 - ii) Standardised Comprehensive Assessment Procedure, Functional Status, Care Team (from October 2005);
 - iii) Social Circumstances (from March 2006); and
 - iv) Adverse Event (from March 2006).

C. Data Elements/Value Domains

1. Value domain development focus on the following data groups more or less in the following order and in alignment with other NEHTA projects:
 - i) Medications;
 - ii) Diagnostic Imaging & Pathology Episode (from July 2005);
 - iii) Reason for Encounter;
 - iv) Problem/Diagnosis;
 - v) Requested Service & Discharge;
 - vi) Clinical Intervention; and
 - vii) Immunisation.

6 APPENDIX A

Example of information requested in the Jurisdictional Visits Worksheet:

Adverse Reaction Data Group

- *Is data group in your system?*
 0=No; 1=Yes, specify system
 2=Planned (specify when and which system)
- *Is this data group a priority for your state?* 0=Not required; 1=Yes, < 12 mnths; 2=Yes, 1-2yrs;
 3=Yes, >2yrs
- *Comments*

<i>Metadata Item Name</i>	<i>Is metadata in your system?</i>	<i>How is this metadata collected?</i>	<i>Is this metadata a priority for your state?</i>	<i>Priority for code set development?</i>	<i>Comments?</i>
Presence					
Agent type					
Agent description					
Type					
Reaction description					
Severity					
First occurrence date					
Status					
Agent description certainty					
Reporting provider					
Status change date					
Status change provider					
Notes					
<i>Other required items</i>					

Example of Problem/Diagnosis data group specifications presented to College/Peak Organisations for comment.

Problem/Diagnosis data group

Definition: The identification, interpretation and assessment of historical and/or current clinical illness and/or complication by a healthcare provider pertaining to a subject of care. The diagnosis can include a disease, condition, injury, poisoning, sign, symptom, abnormal finding, complaint, or other factor influencing health status.

<i>Metadata Item Name</i>	<i>Definition</i>
Type	An indicator to identify the problem/diagnosis as either a primary problem/diagnosis or a complication. (e.g. ICD-10 AM terms).
Description	A description of the diagnosis or problem as determined by the healthcare provider, e.g. ICD-10 AM terms.
Status	An indication of the status of the problem/diagnosis over time, e.g. Active, Inactive.
Start Date	The date or date and time that an event commenced. Incomplete dates allowed for retrospective data collection only.
End Date	The date or date and time that the event ceased. Incomplete dates allowed for retrospective data collection only.
Significance Flag	Indication of the importance of the problem/diagnosis experienced by the subject of care as judged by a healthcare provider, e.g. Yes, No.
Situation of Injury	The place where the external cause of injury, poisoning or adverse effect occurred.
Reporting Provider	Details pertaining to the healthcare provider or organisation who is reporting the event.
Notes	Used to provide additional narrative information in relation to the event.

Question	Response
Are these data items relevant to your specialty area, to send, receive or store information to enhance shared care?	<input type="checkbox"/> Relevant <input type="checkbox"/> Not relevant
If relevant, would you use these data elements if they were available in your current system?	<input type="checkbox"/> Yes <input type="checkbox"/> No
Overall, do you consider the specifications (for this data group) are adequate for the majority (i.e. 80%) of situations?	<input type="checkbox"/> Agree (as specified) <input type="checkbox"/> Disagree Please identify any critical omissions, errors or provide suggestions:
Do you have any significant objections to this data group specification being submitted as a national standard?	<input type="checkbox"/> No <input type="checkbox"/> Yes If Yes, please summarise the objections:

8 APPENDIX C: ACRONYMS & ABBREVIATIONS

TERM	DEFINITION
ACIR	Australian Childhood Immunisation Register
AHMAC	Australian Health Ministers Advisory Council
AIHW	Australian Institute of Health and Welfare
AMDT	Australasian Medicines & Devices Terminology
ATAGI	Australian Technical Advisory Group for Immunisation
AWG	AHMAC Working Group
CDS	Clinical Data Standards
CISP	Clinical Information System Program
CRG	Clinical Reference Group
DoHA	Department of Health and Ageing
DSTU	Draft Specification for Trial Use
EHR	Electronic Health Record
GP	General Practitioner
HDSC	Health Data Standards Committee
HL7	Health Level Seven
INI	Initial Contact Information
ISO/IEC 11179	International standard for Metadata Registries (previously International standard for the specification and standardisation of data elements)
NAC	NEHTA Advisory Committee
NCCH	National Centre for Classification in Health
NCIRS	National Centre for Immunisation Research and Surveillance of Vaccine Preventable Disease
NEHTA	National E-Health Transition Authority
NHDD	National Health Data Dictionary
NISO	National Information Standards Organisation
NMDS	National Minimum Data Set
OACIS	Open Architecture Clinical Information System
ONI	Ongoing Needs Identification

TERM	DEFINITION
PoCCS	Point of Care Clinical Information System
SCTT	Service Coordination Tool Templates
SIMC	Statistical Information Management Committee
SNOMED-CT	Systemised Nomenclature of Medicine - Clinical Terms