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**Business requirements for health  
summary records —**

**Part 2:  
Environmental scan**

*Exigences d'affaire pour les enregistrements de santé sommaires —  
Partie 2: Balayage environnemental*



Reference number  
ISO/TR 12773-2:2009(E)

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## Foreword

ISO (the International Organization for Standardization) is a worldwide federation of national standards bodies (ISO member bodies). The work of preparing International Standards is normally carried out through ISO technical committees. Each member body interested in a subject for which a technical committee has been established has the right to be represented on that committee. International organizations, governmental and non-governmental, in liaison with ISO, also take part in the work. ISO collaborates closely with the International Electrotechnical Commission (IEC) on all matters of electrotechnical standardization.

International Standards are drafted in accordance with the rules given in the ISO/IEC Directives, Part 2.

The main task of technical committees is to prepare International Standards. Draft International Standards adopted by the technical committees are circulated to the member bodies for voting. Publication as an International Standard requires approval by at least 75 % of the member bodies casting a vote.

In exceptional circumstances, when a technical committee has collected data of a different kind from that which is normally published as an International Standard ("state of the art", for example), it may decide by a simple majority vote of its participating members to publish a Technical Report. A Technical Report is entirely informative in nature and does not have to be reviewed until the data it provides are considered to be no longer valid or useful.

Attention is drawn to the possibility that some of the elements of this document may be the subject of patent rights. ISO shall not be held responsible for identifying any or all such patent rights.

ISO/TR 12773-2 was prepared by Technical Committee ISO/TC 215, *Health informatics*.

ISO/TR 12773 consists of the following parts, under the general title *Business requirements for health summary records*:

- *Part 1: Requirements*
- *Part 2: Environmental Scan*

## Introduction

Consumer, clinician, industry and government demands for improved safety, quality, effectiveness and efficiency in healthcare are driving the need for more “connected” care, which in turn requires improved communication of clinical information between multiple providers and subjects of care. Internationally, various “summary” or “snapshot” health records have been developed to meet these communication needs. Many similarities are evident in these initiatives, but their conceptual foundations have not always been articulated with a set of business requirements as their starting point.

The purpose of this part of ISO/TR 12773 is to identify the common business requirements these initiatives are seeking to address as well as the requirements for standards for health summary records (HSRs) that can guide future HSR development efforts.

Any future ISO initiative to create standards for a generic HSR specification or specifications for one or more types of HSR will leverage existing initiatives and adopt/adapt relevant standards utilized therein. Such HSR specifications are unlikely to require new standards, given that much of their content is deemed “common”, “core”, “essential” or “emergency” in nature and is therefore part of most EHR initiatives world-wide as evidenced in this part of ISO/TR 12773.

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# Business requirements for health summary records —

## Part 2: Environmental scan

### 1 Scope

This part of ISO/TR 12773 reviews a series of initiatives and implementations worldwide that for purposes of this Technical Report are collectively called health summary records (HSRs). It provides an environmental scan and descriptive information on HSR initiatives internationally, including “lessons learned”.

The environmental scan was completed by performing web searches and obtaining publicly available documentation on key projects. Project sponsors and/or authorities were contacted as needed to gather additional information and clarify questions and issues arising out of the review.

### 2 Terms and definitions

For the purposes of this document, the following terms and definitions apply.

#### 2.1

##### **agent**

person, device or software that performs a role in a healthcare activity

#### 2.2

##### **client**

##### **patient**

individual who is a subject of care

[ISO/TR 20514:2005, definition 2.30]

**NOTE** The terms “client” and “patient” are synonymous but the usage of one or the other of these terms tends to differ between different groups of health professionals. Clinicians working in a hospital setting and medical practitioners in most clinical settings will use the term “patient” whereas allied health professionals may use the term “client”.

#### 2.3

##### **clinical information**

information about a person, relevant to his or her health or healthcare

[ISO 13606-1:2008, definition 3.13]

#### 2.4

##### **clinician**

health professional who delivers health services directly to a patient/client

[ISO/TR 20514:2005, definition 2.6]

## 2.5

### **consumer**

individual who may become a subject of care

[ISO/TS 20514:2005, definition 2.9]

## 2.6

### **data object**

collection of data that has a natural grouping and may be identified as a complete entity

## 2.7

### **electronic health record**

#### **EHR**

〈basic generic form〉 repository of information regarding the health status of a subject of care, in computer processable form

[ISO/TR 20514:2005, definition 2.11]

## 2.8

### **electronic health record composition**

#### **EHR composition**

set of information committed to one EHR by one agent, as a result of a single clinical encounter or record documentation

EXAMPLES Progress Note, radiology report, referral letter, clinic visit record, discharge summary, functional health assessment, diabetes review.

## 2.9

### **electronic health record extract**

#### **EHR extract**

a) unit of communication of the EHR which is itself attestable and which consists of one or more EHR compositions

[ISO/TR 20514:2005, definition 2.13]

b) part or all of the electronic health record of a subject of care communicated between an EHR provider system and an EHR recipient

NOTE Adapted from ISO 13606-1:2008.

## 2.10

### **electronic health record (EHR) — integrated care (ICEHR)**

repository of information regarding the health status of a subject of care in computer processable form, stored and transmitted securely, and accessible by multiple authorized users and having a standardized or commonly agreed logical information model that is independent of EHR systems and whose primary purpose is the support of continuing, efficient and quality integrated healthcare and which contains information that is retrospective, concurrent and prospective

NOTE 1 Adapted from ISO/TR 20514:2005.

NOTE 2 The definition of the EHR for integrated care should be considered the primary definition of an electronic health record. The definition of a basic-generic EHR is given only for completeness.

## 2.11

### **electronic health record repository**

database in which electronic health record information is persisted



**2.12**  
**electronic health record — shareable**  
**EHR — shareable**

electronic health record with a standardized information model, which is independent of electronic health record systems and accessible by multiple authorized users

NOTE 1 The shareable EHR *per se* is an artefact between a basic-generic EHR and the integrated care EHR (ICEHR) which is a specialization of the shareable EHR. The shareable EHR is probably of little use without the additional clinical characteristics that are necessary for its effective use in an integrated care setting.

NOTE 2 Whilst the ICEHR is the target for interoperability of patient health information and optimal patient care, it should be noted that the large majority of EHRs in use at present are not even shareable let alone have the additional characteristics required to comply with the definition of an integrated care EHR. A definition of a basic-generic EHR has therefore been included to acknowledge this current reality.

**2.13**  
**electronic health record system**  
**EHR system**

system for recording, retrieving and manipulating information in electronic health records

[ISO 13606-1:2008, definition 3.26]

**2.14**  
**health**

state of complete physical, mental and social well-being and not merely the absence of disease or infirmity

[WHO: 1948]

**2.15**  
**healthcare**

activities, services, or supplies related to the health of an individual

[ISO 18308:—, definition 3.28]

**2.16**  
**healthcare activity**

undertakings (assessments, interventions) that comprise a healthcare service

**2.17**  
**healthcare organization**

organization involved in the direct or indirect provision of healthcare services to an individual or to a population

[ISO/EN 13606-1:2008]

**2.18**  
**healthcare service**

service provided with the intention of directly or indirectly improving the health of the person or populations to whom it is provided

[ISO/EN 13606-1:2008]

**2.19**  
**health condition**

a) aspect of a person or group's health that requires some form of intervention

[Canada Health Infoway EHRS Blueprint v1.0: 2003]

NOTE These interventions could be anticipatory or prospective, such as enhancing wellness, wellness promotion or illness prevention (e.g. immunization).

- b) symptoms, health problems (not yet diagnosed), diagnoses (known or provisional), e.g. diabetes, physiological changes that affect the body as a whole or one or more of its parts, e.g. benign positional vertigo and/or affect the person's well-being, e.g. psychosis, and/or affect the person's usual physiological state, e.g. pregnancy, lactation

[Canada Health Infoway, iEHR Clinical Standards Glossary 2007]

**2.20**  
**health information**  
see **clinical information** (2.3)

**2.21**  
**health problem**  
see **health condition** (2.19); see **problem** (2.34)

**2.22**  
**health professional**  
person who is authorized by a recognised body to directly provide certain healthcare services

NOTE Adapted from ISO/TR 20514:2005 and EN 13940-1:2007.

**2.23**  
**health record**  
repository of information regarding the health of a subject of care

[ISO/TR 20514: 2005, definition 2.25]

**2.24**  
**health record extract**  
attestable unit of communication of all or part of a health record.

**2.25**  
**health summary record**  
health record extract comprising a standardized collection of clinical and contextual information (retrospective, concurrent, prospective) that provides a snapshot in time of a subject of care's health information and healthcare

**2.26**  
**HL7 Clinical Document Architecture**  
**CDA**  
documentation that defines structure and semantics of medical documents for the purpose of exchange

NOTE CDA documents are encoded in Extensible Mark-up Language (XML). They derive their meaning from the HL7 Reference Information Model (RIM) and use the HL7 Version 3 Data Types, which are part of the HL7 RIM.

[HL7 International- HL7 CDA Release 2.0]

**2.27**  
**integrated care electronic health record (EHR) (ICEHR)**  
see **electronic health record (EHR) — for integrated care (ICEHR)** (2.10)

**2.28**  
**metadata**  
a) information stored in a data dictionary that describes the content of a document

[ISO/TR 22221:2006; definition 2.10]

NOTE Metadata can include data structure, constraints, types, formats, authorizations, privileges, relationships, distinct values, value frequencies, keywords, and users of the database sources loaded in the EHR repository and the EHR repository itself. Metadata facilitates information management for users, developers and administrators.

b) data that define object class and property for the information collected

[ISO 13606-1:2008, definition 3.37]

## 2.29

### **organization**

unique framework of authority within which a person or persons act, or are designated to act towards some purpose

[ISO 6523-1:1998, definition 3.1]

## 2.30

### **personal health record**

#### **PHR**

electronic, universally available, lifelong resource of health information needed by individuals to make health decisions

NOTE Individuals own and manage the information in the PHR, which comes from healthcare providers and the individual. The PHR is maintained in a secure and private environment, with the individual determining rights of access. The PHR is separate from and does not replace the legal record of any provider

[AHIMA E-HIM PHR Work Group 2005]

## 2.31

### **physician**

health professional who has successfully completed the prescribed course of studies in medicine in a recognised medical school and who has met the qualifications for licensure in the practice of medicine set by the state or country in which they are practicing

## 2.32

### **practice electronic health record (EHR) system**

EHR system that a clinician or group of clinicians uses to document the care provided to a subject of care in their healthcare organization

NOTE In primary and ambulatory care settings, the practice EHR is usually referred to as an electronic medical record (EMR). In acute care settings such as hospitals, it is commonly referred to as an electronic patient record (EPR). In community care settings including home care settings, it may be referred to as an electronic client record (ECR) or an EPR.

## 2.33

### **primary care**

overall management of a subject of care's health problems, including direct delivery of care as well as coordinating care to specialists and other providers in a gatekeeper system, i.e. a system where the primary care provider acts on behalf of their patients to manage and prioritize access to required healthcare services

NOTE Adapted from Canada Health Infoway iEHR Clinical Standards Glossary 2007.

## 2.34

### **problem**

entity for which an assessment is made and a plan or intervention is initiated

[NZ EMR:1998]

NOTE The term "issue" is often used rather than "problem" by many allied health professions, especially in the more social/psychological disciplines. The term "condition" is also sometimes used to describe pregnancy and other non-disease health states which nevertheless usually involve interaction with a health system.

**2.35**

**provider**

person or organization involved in or associated with the delivery of healthcare to a subject of care, or caring for the wellbeing of a subject of care

**2.36**

**records**

information created, received, and maintained as evidence and information by an organization or person, in pursuance of legal obligations or in the transaction of business

[ISO 15489-1:2001, definition 3.15]

**2.37**

**referral**

practice of a provider sending a subject of care to receive healthcare services or a clinical opinion from another provider when the sending provider is not qualified or prepared to offer such services or opinion

NOTE 1 Adapted from Canada Health Infoway iEHR Standards Glossary 2007.

NOTE 2 A referral letter is a clinical document that accompanies the referral request. It contains the reason for the referral and includes details of the subject's health condition(s) and other additional health information relevant to the referral, as well as a date and the authentication of the referring provider.

**2.38**

**secondary use**

(of a healthcare record) any legitimate use of a healthcare record other than for the purpose of supporting the direct delivery of healthcare services to the subject of care

EXAMPLES Medico-legal, quality management, clinical research, epidemiology, population health, health administration, financial, educational or health service planning purposes.

**2.39**

**security**

combination of confidentiality, integrity and availability

**2.40**

**service**

number of processes, involving an organization in the provision of specific objectives

[ISO 12967-1:—, definition 3.4.7]

**2.41**

**shareable EHR**

see **electronic health record — shareable** (2.12)

**2.42**

**shared EHR**

see **electronic health record — shareable** (2.12)

**2.43**

**specialist**

(physician) whose practice is limited to a particular area of medicine in which the physician is usually certified by a recognized board or college of physicians

**2.44**

**standard**

document, established by consensus and approved by a recognised body that provides, for common and repeated use, rules, guidelines or characteristics for activities or their results, aimed at achievement of the optimum degree of order in a given context

[ISO/IEC Guide 2:2004, definition 3.2]

**2.45****subject of care**

one or more persons scheduled to receive, receiving, or having received healthcare

NOTE 1 Adapted from ISO 13606-1: 2008.

NOTE 2 The terms “patient” and “client” are synonymous with subject of care in a health record context and are commonly used instead of the more formal term “subject of care”.

NOTE 3 The term “consumer” is also often used as a synonym in this context. However, it should be noted that a consumer may not necessarily be a subject of care since it can be argued that it is possible for a consumer to have a health record without ever having received a healthcare service.

**3 Initiatives reviewed**

Table 1 lists the initiatives that were reviewed as part of the environmental scan, along with relevant information regarding the lead for the initiative, web links and key characteristics. Initiatives are listed in alphabetical order by country and additional analysis information has been added via a column on the far right in the table. Because of the diversity and number of initiatives identified, detailed comparisons were not undertaken beyond summarizing key findings in Clause 4, from which the business requirements in ISO/TR 12773-1 were largely derived.

Details of well-known/publicized initiatives have been included in Clause 5.

Table 1 — HSR Environmental scan — Summary

Country	Initiative	Lead	Link(s)	Key Characteristics
Australia	National ehealth Data and Content Specifications	National E-Health Transition Authority (NEHTA)	<a href="http://www.nehta.gov.au">http://www.nehta.gov.au</a> - NEHTA <a href="http://www.nehta.gov.au/index.php?option=com_content&amp;task=view&amp;id=235&amp;Itemid=454">http://www.nehta.gov.au/index.php?option=com_content&amp;task=view&amp;id=235&amp;Itemid=454</a> National E-Health Data Group Library <a href="http://www.nehta.gov.au/index.php?option=com_content&amp;task=view&amp;id=139&amp;Itemid=383">http://www.nehta.gov.au/index.php?option=com_content&amp;task=view&amp;id=139&amp;Itemid=383</a> Standards Catalogue	Standards and specifications include detailed specifications for high priority clinical data groups and the structured content of clinical communications.  The standardized data specifications can be used to construct various types of care summary records.  Content specifications have been developed for Discharge Summary and GP to Specialist/Acute Care Referral.
Asia - Korea	Standard Chief Complaint Set Created from Discharge Summary, Applicable to EMR: Short Term Experience in Seoul National University Bundang Hospital	Ho Jun Chin et al; Department of Internal Medicine & Department of Pediatrics Seoul National University College of Medicine Seoul, Korea	<a href="http://kosmi.snubi.org/2003_fall/main.html">http://kosmi.snubi.org/2003_fall/main.html</a> — October 22, 2006 — Oral 6 session	CDA documents are used for discharge summaries and for creation of a standard chief complaint set in Korea.

Table 1 (continued)

Country	Initiative	Lead	Link(s)	Key Characteristics
Canada – Canada Health Infoway	Clinical Profile	Canada Health Infoway	<p><a href="http://www.infoway-inforoute.ca/en/home/home.aspx">http://www.infoway-inforoute.ca/en/home/home.aspx</a> - Home</p> <p><a href="http://knowledge.infoway-inforoute.ca/en/">http://knowledge.infoway-inforoute.ca/en/</a> - Knowledge gateway</p> <p><a href="http://forums.infoway-inforoute.ca/webx?14@894.p5spaPOfd94.48@.eeda7b9">http://forums.infoway-inforoute.ca/webx?14@894.p5spaPOfd94.48@.eeda7b9</a> – Pan-Canadian Standards Forum</p> <p>or</p> <p><a href="http://forums.infoway-inforoute.ca/webx?14@128.CMlb6alidh2K.29@.eeda7b9">http://forums.infoway-inforoute.ca/webx?14@128.CMlb6alidh2K.29@.eeda7b9</a> – Standards Collaborative Working Group 2 Forum</p> <p>See files on either of above sites:</p> <ul style="list-style-type: none"> <li>— Message Definition Worksheet;</li> <li>Scope &amp; Package Tracking Framework &amp; Word views of message models</li> </ul>	<p>A Clinical Profile is a key component of Infoway's pan-Canadian HL7v3 messaging standards for sharing clinical information in the context of a shared EHR.</p> <p>Profile is generated based on a query to a shared EHR repository for all relevant data on a given patient. Data returned is determined by the query parameters.</p>
Canada – Alberta	Physician Office System Program Medical Summary for Transfer of Patient Data	Alberta Health & Wellness (Alberta Health Ministry) – Alberta Health Information Standards Committee	<p><a href="http://www.health.alberta.ca">http://www.health.alberta.ca</a></p> <p><a href="http://www.health.alberta.ca/about/HI_SCA_standards.html">http://www.health.alberta.ca/about/HI_SCA_standards.html</a> - look under Physician Office System</p> <p><a href="http://www.health.alberta.ca/about/HI_SCA_POSP_xferPatData.pdf">http://www.health.alberta.ca/about/HI_SCA_POSP_xferPatData.pdf</a></p>	<p>Point-to-point sharing</p> <p>Scope restricted to permanent transfer of patient records between physicians or from one EMR vendor system to a different one</p> <p>Draft specification released July 2005</p> <p>Leverages British Columbia and Ontario initiatives (as listed in this table)</p>
Canada – British Columbia	Electronic Medical Summary (e-MS)	British Columbia Ministry of Health eMS Project	<p>Vancouver Island Health Authority, BC</p> <p><a href="http://www.e-ms.ca/">http://www.e-ms.ca/</a></p>	<p>Point-to-point primary care physician information sharing</p> <p>Component (planned) of a provincial (shared) EHR</p> <p>Detailed specification based on HL7 CDA; HL7 v3 messages – all artefacts posted on the website</p>

Table 1 (continued)

Country	Initiative	Lead	Link(s)	Key Characteristics
Canada – British Columbia	Electronic Medical Summary (e-MS): lessons learned from other jurisdictions. Victoria BC (CA): Vancouver Island Health Authority.	Protti, DJ 2004 June 16	<a href="http://www.uvic.ca/">http://www.uvic.ca/</a> - School of Health Information Sciences, University of Victoria, BC	The report reviewed initiatives implemented or underway in other Canadian jurisdictions (primarily Alberta and Ontario) as well as internationally. The analysis also included a survey of 35 individuals, primarily BC physicians, soliciting their views on critical success factors for the electronic exchange of patient summary information between providers and across healthcare sectors.  Some of the key findings have been incorporated into Clause 5 of this Technical Report.
Canada - Ontario	Ontario Clinical Management System Core Dataset	OntarioMD (under the auspices of the Ontario Medical Association)	<a href="http://www.ontariomd.ca">http://www.ontariomd.ca</a> click on CMS Standards link <a href="http://www.cred.ca/skmt/docs/attachments/357/CMS%20SpecificationV2%200%20April%2016%202007.pdf">http://www.cred.ca/skmt/docs/attachments/357/CMS%20SpecificationV2%200%20April%2016%202007.pdf</a> — Clinical Management System specification April 2007, includes Core Dataset <a href="http://www.skmtportal.cred.ca/search.aspx?artid=357">http://www.skmtportal.cred.ca/search.aspx?artid=357</a>	Point-to-point sharing  A core dataset (CDS) that can be used to enable the export and import of all administrative and clinical information needed to provide continuity of patient care when primary care physicians switch from one EMR vendor system to a different EMR vendor system.  The CDS is approved for use as a data export and import mapping schema from one EMR system to another.  The CDS data groups include: — family history, past health history; problem list, risk factors, allergies & adverse reactions, medications, immunizations, lab results, other treatments and reports.



Table 1 (continued)

Country	Initiative	Lead	Link(s)	Key Characteristics
Canada - Ontario	COMPETE Project – Computerization of Medical Practices for the Enhancement of Therapeutic Effectiveness	Anne Holbrook MSc, MD, PharmD, FRCP(C), FISPE Principle Investigator E-mail: holbrook@mcmaster.ca	<a href="http://www.compete-study.com">http://www.compete-study.com</a>	COMPETE I Core Data Set implemented based on Ministry of Health's Core Data Set and Ontario Smart Systems for Health Agency Ontario Health Profile COMPETE II Extended the Core Data Set to include chronic disease management tracking data COMPETE III Utilized the HL7v3 messages developed by the British Columbia e-MS project (see e-MS reference in this table) Context for studies: shared EHR and chronic disease management. Use of EMRs and clinical decision support tools in primary care as well as diabetes and vascular disease tracking systems.
Europe – EU Commission	Report – State of Developing Electronic Patient Summaries in European Union Member States and Beyond (2007)	EU Commission eHealth Action Plan eHealth Stakeholder Group	<a href="http://www.ehealthnews.eu/content/view/full/605/62/">http://www.ehealthnews.eu/content/view/full/605/62/</a> - European eHealth News Portal	The EC report analyzes the current state of developing electronic patient summaries in European Union Member States and beyond. It highlights the benefits of such summaries and also the difficulties that need to be overcome to make use of patient summaries in different countries.
Europe - Finland	EHR Strategy Finland 2005	Finland Ministry of Social Affairs and Health	<a href="http://www.cairhio.org/crweb-files/docs-hie/Helsinki%20Univ%20-%20EHR%20Strategy%20Finland%202005.pdf">http://www.cairhio.org/crweb-files/docs-hie/Helsinki%20Univ%20-%20EHR%20Strategy%20Finland%202005.pdf</a> <a href="http://b2cpro.vtt.fi/documents/usa/2007-03-mayo-vesa.pdf">http://b2cpro.vtt.fi/documents/usa/2007-03-mayo-vesa.pdf</a> - Interoperability in Finland – a review of past, present time and future – Dr. Vesa Pakarinen, Mayo Clinic Presentation – March 9, 2007 <a href="http://www.stm.fi/Resource.phx/publis hing/documents/10546/index.htm">http://www.stm.fi/Resource.phx/publis hing/documents/10546/index.htm</a> – Finland eHealth Roadmap	Intend to create a common minimum dataset to be shared by all practitioners in healthcare Structured Data to include information that has the most significance in making decisions about treatments: Patient and Provider ID Episode and chain codes Risk information, e.g. smoking Diagnosis codes Procedure codes Tests (Lab & Imaging) Medications Plus links to free text.

Table 1 (continued)

Country	Initiative	Lead	Link(s)	Key Characteristics
Europe - Germany	Introduction of the Clinical Document Architecture Release 2 in Germany- the Sciphox experience (2006)	German health ministry in collaboration with HL7 Germany	<a href="http://sciphox.hl7.de/">http://sciphox.hl7.de/</a> <a href="http://ihic.hl7.de/proceedings/C1-KH.pdf">http://ihic.hl7.de/proceedings/C1-KH.pdf</a> - Dr. Kai U. Heitmann <a href="mailto:hi7@kheitmann.nl">hi7@kheitmann.nl</a>	Nationwide German Project – 2 phases: Phase 1 - Standardization of Communication between Information Systems in Physician Offices and Hospitals using XML Phase 2 – Creation of Care Record Summary (CDA R2) documents
Europe - Sweden	National Patient Summary Project (2007-2010)	Carelink Ministry of Health & Social Affairs National Board of Health and Welfare	<a href="http://www.carelink.se/">http://www.carelink.se/</a> — Carelink <a href="http://www.carelink.se/en/the_initiative/access_to_care_information/national_patient_summary/">http://www.carelink.se/en/the_initiative/access_to_care_information/national_patient_summary/</a> — National Patient Summary	Initial implementation underway To include basic care information, for example diagnoses, medical reports and discharge summaries. PKI will be required for access to the summary.
ISO	ISO 21549-3:2004 Health informatics - Patient healthcare data – Part 3: Limited clinical data	TC 215	<a href="http://www.iso.org/iso/iso_catalogue/catalogue_tc/catalogue_tc_browse.htm?commid=54960">http://www.iso.org/iso/iso_catalogue/catalogue_tc/catalogue_tc_browse.htm?commid=54960</a> – ISO Catalogue of Publications	Published in 2004 and in use in various healthcare projects throughout Europe. Limited clinical dataset embedded on a patient healthcare for use in emergency and other unscheduled care situations. 3 datasets: — limited emergency dataset, e.g. allergies; medications; significant problems; — blood grouping and transfusion record dataset; — immunizations received dataset.

Table 1 (continued)

Country	Initiative	Lead	Link(s)	Key Characteristics
New Zealand	Medical Warnings System	New Zealand Ministry of Health	<a href="http://www.nzhis.govt.nz/moh.nsf/bag/esns/54">http://www.nzhis.govt.nz/moh.nsf/bag/esns/54</a> — New Zealand Health Information Service	<p>The Medical Warnings System is a value-added service closely aligned with the National Health Index. It is designed to warn healthcare providers of the presence of any known risk factors that may be important when making clinical decisions about patient care.</p> <p>The MWS comprises the following features:</p> <ul style="list-style-type: none"> <li>— medical warnings incorporating adverse medical reactions and significant medical conditions;</li> <li>— event summaries incorporating identification of the facility where the patient's medical record is located;</li> <li>— donor information incorporating donor summaries and healthcare user contact details.</li> </ul> <p>The MWS was initially part of the National Master Patient Index, implemented in 1977.</p>
NHS UK – England	NHS Care Records Service – Summary Care Record	NHS	<a href="http://www.connectingforhealth.nhs.uk/systemsandservices/nhsconnect">http://www.connectingforhealth.nhs.uk/systemsandservices/nhsconnect</a> — NHS Connecting for Health <a href="http://www.nhs-care-records.nhs.uk/">http://www.nhs-care-records.nhs.uk/</a> NHS Care Records Service (patient site)	<p>Shared EHR context</p> <p>The Summary Care Record component of the Care Records Service will be comprised of:</p> <ul style="list-style-type: none"> <li>— essential elements of a patient's electronic record, extracted from general practice notes, and</li> <li>— essential elements relating to that person from other organizations where they have received care.</li> </ul> <p>The first implementations of the SCR include data on allergies, current prescriptions and any adverse reactions to medications.</p>

Table 1 (continued)

Country	Initiative	Lead	Link(s)	Key Characteristics
NHS UK - England	National Dataset Initiatives	NHS Information Centre (formerly the Dataset Development Programme)	<p><a href="http://www.ic.nhs.uk/">http://www.ic.nhs.uk/</a> — NHS Information Centre</p> <p><a href="http://www.ic.nhs.uk/statistics-and-data-collections">http://www.ic.nhs.uk/statistics-and-data-collections</a> — Statistics &amp; Data Collections</p> <p><a href="http://www.ic.nhs.uk/our-services/standards-and-classifications/datasets/document-downloads">http://www.ic.nhs.uk/our-services/standards-and-classifications/datasets/document-downloads</a> — Document Downloads</p> <p><a href="http://www.ic.nhs.uk/our-services/standards-and-classifications/datasets">http://www.ic.nhs.uk/our-services/standards-and-classifications/datasets</a> — National Datasets Service</p>	<p>The NHS has created National Service Frameworks to promote equality and high standards of care across the UK.</p> <p>Disease specific datasets for each disease area have been created to support monitoring and evaluation, e.g. cancer; mental health; heart disease; diabetes. Several of these datasets are defined as "core" or "minimum" datasets, e.g. mental health. Details of each dataset can be found on the site.</p> <p>A 2003/04 initiative to create a Generic Core Dataset across these disease areas revealed very few areas of overlap or duplication because the data captured by each sector is very specialized.</p> <p><u>Technical Report author's note:</u> small sub-sets of these speciality datasets could serve as optional extensions to a generic HSR.</p>
NHS UK - Scotland	Emergency Care Summary (ECS)		<p><a href="http://www.nhsns.org/supplementary-pages/news_detail.php?newsid=60">http://www.nhsns.org/supplementary-pages/news_detail.php?newsid=60</a> — NHS Scotland's Emergency Care Summary</p> <p><a href="http://www.scimp.scot.nhs.uk/clinical-ecs.html">http://www.scimp.scot.nhs.uk/clinical-ecs.html</a> — Scottish Clinical Information in Practice (SCIMP) — details on ECS</p> <p><a href="http://www.scimp.scot.nhs.uk/documents/RCGPsSummaryCareRecordGPsSummaryFinal.pdf">http://www.scimp.scot.nhs.uk/documents/RCGPsSummaryCareRecordGPsSummaryFinal.pdf</a> — Royal College of GPs summary document</p>	<p>Shared EHR context</p> <p>Provides a primary care physician (General Practitioner – GP) summary dataset for use by other clinicians in unscheduled care settings.</p> <p>The ECS contains patient information on: name, date of birth, community health index (CHI) number, information on prescribed medication and allergies.</p> <p>Information is copied from GP computer systems, is stored electronically and is available only with consent from the patient to staff in hospital emergency departments, to doctors and nurses in all out of hours medical centers and the NHS 24 staff (telephone health line).</p>

Table 1 (continued)

Country	Initiative	Lead	Link(s)	Key Characteristics
NHS UK - Scotland	National Clinical Dataset Development Program (NCDDP)	NHS Scotland – under the Information Services Division	<a href="http://www.isdscotland.org/isd/4998.htm">http://www.isdscotland.org/isd/4998.htm</a> — NCDDP	<p>Similar to the NHS England National Dataset Initiatives.</p> <p>A similar project to define a Generic Core Dataset as a component of a Scottish Social Care Data Standards Project was undertaken in 2004 under the auspices of the national program.</p> <p>See <a href="http://193.195.78.72/scds/files/eCART%20Dataset%20Consultation%20Final%20Document1.pdf">http://193.195.78.72/scds/files/eCART%20Dataset%20Consultation%20Final%20Document1.pdf</a>.</p>
NHS UK - Wales	Individual Health Record	NHS Wales	<a href="http://www.wales.nhs.uk">http://www.wales.nhs.uk</a> <a href="http://www.wales.nhs.uk/IHC/home.cfm">http://www.wales.nhs.uk/IHC/home.cfm</a> - Informing Healthcare <a href="http://www.wales.nhs.uk/ihc/page.cfm?pid=25883">http://www.wales.nhs.uk/ihc/page.cfm?pid=25883</a> <a href="http://www.wales.nhs.uk/ihc/page.cfm?pid=25881">http://www.wales.nhs.uk/ihc/page.cfm?pid=25881</a> — Individual Health Record in Out-of-Hours Care <a href="http://www.ehprimarycare.com/News/3269/informing_healthcare_announce_next_wales_ohr_sites">http://www.ehprimarycare.com/News/3269/informing_healthcare_announce_next_wales_ohr_sites</a> — Extension of IHR	<p>Shared EHR</p> <p>Provides an extract of the GP record for out-of-hours and emergency care.</p> <p>Extracts all coded data from GP systems, except sensitive data such as sex changes or Sexually Transmitted Infections.</p> <p>Works on an explicit consent basis. Each time the system is used, the patient must give their consent.</p> <p>In emergencies, the doctor can click the emergency button to signal the patient could not be asked for their consent.</p>
United Kingdom - England Other Initiatives	Myocardial Infarction National Audit Project (MINAP) (1998 forward)	Royal College of Physicians London Relocated in 2008 to National Institute for Clinical Outcomes Research, University College London	<a href="http://www.rcplondon.ac.uk/clinical-standards/organisation/partnership/Pages/MINAP.aspx">http://www.rcplondon.ac.uk/clinical-standards/organisation/partnership/Pages/MINAP.aspx</a> <a href="http://www.uclh.nhs.uk/">http://www.uclh.nhs.uk/</a> — University College London	<p>The criteria and principles for development of standardized health summary record content outlined in the Technical Report were adapted from this project.</p> <p>A broadly based steering group developed a dataset for acute myocardial infarction (AMI). This allowed clinicians to examine the management of myocardial infarction within their hospitals against targets specified by the National Service Framework for Coronary Heart Disease (NSF).</p> <p>The latest version of the MINAP Core Data Set can be found on the Royal College website.</p>

Table 1 (continued)

Country	Initiative	Lead	Link(s)	Key Characteristics
United States	Continuity of Care Document (CCD) (2007)	HL7, ASTM	<p><a href="http://www.ahima.org/meetings/lc/documents/Alschuler_HIInLTCPanelJune06.rev.ppt">http://www.ahima.org/meetings/lc/documents/Alschuler_HIInLTCPanelJune06.rev.ppt</a> — Content &amp; Interoperability Standards Panel: HL7 CDA — Liora Alschuler</p> <p><a href="http://www.alschulerassociates.com/library/presentations/Alschuler.CCD.ppt">http://www.alschulerassociates.com/library/presentations/Alschuler.CCD.ppt</a> — CCD: Liora Alschuler</p> <p><a href="http://www.neotool.com/blog/2008/07/29/continuity-of-care-document-for-clinical-data-exchange/">http://www.neotool.com/blog/2008/07/29/continuity-of-care-document-for-clinical-data-exchange/</a> - Neotool blog</p> <p><a href="http://www.hl7.org/search/search.cfm">http://www.hl7.org/search/search.cfm</a> — CCD final specification</p>	<p>The CCR is a standardized dataset that can be used to constrain the CDA specifically for summary documents.</p> <p>CCD maps the CCR elements into a CDA representation.</p>
United States	Continuity of Care Record (CCR) (2006) (XML)	ASTM International	<p><a href="http://www.astm.org">http://www.astm.org</a> — search for publication E2369</p> <p>Up-to-date information on adoption and deployment can be found at <a href="http://www.ccrstandard.com/">http://www.ccrstandard.com/</a> — The CCR Standard Resource site.</p>	<p>Undertaken in response to the need to organize and make transportable a set of basic patient information consisting of the most relevant and timely facts about a patient's health history and current health status.</p> <p>The CCR is a snapshot of the most relevant patient information intended for timely point-to-point sharing between providers to inform care decisions.</p>

Table 1 (continued)

Country	Initiative	Lead	Link(s)	Key Characteristics
United States	Care Record Summary - HL7 Clinical Document Architecture (CDA) Implementation Guide for CDA Release 2 — Level 1 and 2 (U.S. realm), 2006	HL7 International	<p>Care Record Summary Level 1 IG (2005)</p> <p><a href="http://www.hl7.org/documentcenter/balots/2005may/downloads/CDA_Care_Record_SummaryIG_Level1.zip">http://www.hl7.org/documentcenter/balots/2005may/downloads/CDA_Care_Record_SummaryIG_Level1.zip</a></p> <p>Care Record Summary Level 2 IG (2005)</p> <p><a href="http://www.hl7.org/documentcenter/balots/2005may/downloads/CDA_Care_Record_SummaryIG_Level2.zip">http://www.hl7.org/documentcenter/balots/2005may/downloads/CDA_Care_Record_SummaryIG_Level2.zip</a></p> <p>Overview of Care Record Summary Implementation Guides</p> <p><a href="http://www.himss.org/content/files/CDAR2IG.pdf">http://www.himss.org/content/files/CDAR2IG.pdf</a></p> <p>HL7 CDA Resource Page - <a href="http://hl7book.net/index.php?title=CDA">http://hl7book.net/index.php?title=CDA</a></p> <p>CDA R2 CRS, June 2006 (US Realm)</p> <p><a href="http://www.hl7.org/search/search.cfm">http://www.hl7.org/search/search.cfm</a></p>	<p>A Care Record Summary document contains a patient's relevant health history for some time period. It is intended for communication between health care providers and applies to Discharge Summaries, transfer summaries and similar types of summary documents.</p> <p>The CRS prescribes the content that is common for every inpatient stay or transfer of care.</p>
United States	IHE Medical Summary Integration Profile	IHE	<p><a href="http://www.ihe.net/Technical_Framework/index.cfm#pcc">http://www.ihe.net/Technical_Framework/index.cfm#pcc</a> — Patient Care Coordination Framework (includes Medical Summary IP)</p> <p><a href="http://wiki.ihe.net/index.php?title=Medical_Summaries_Profile">http://wiki.ihe.net/index.php?title=Medical_Summaries_Profile</a></p> <p><a href="http://www.ihe.net/Connectathon/index.cfm">http://www.ihe.net/Connectathon/index.cfm</a> — IHE Connectathons</p>	<p>The Medical Summary Integration Profile and the Medical Summary Content specification address clinical documents that contain the most relevant portions of information about a particular patient.</p> <p>They are intended for a specific provider or a broad range of potential providers in different settings and are usually created and accessed at points in time of transfers of care such as referrals or discharges.</p>

Table 1 (continued)

Country	Initiative	Lead	Link(s)	Key Characteristics
United States	Veterans' Computerized Patient Record System – Veterans' Health Information Systems and Technology Architecture (Vista) – Health Summary Record	U.S. Government Department of Veterans Affairs	<p><a href="http://www.va.gov/">http://www.va.gov/</a> — Veterans' Affairs</p> <p><a href="http://www.va.gov/vdl/application.asp?appid=63">http://www.va.gov/vdl/application.asp?appid=63</a> – VHA Software Document Library – Computerized Patient Record System (CPRS) – Health Summary technical &amp; user manuals.</p>	<p>VISTA is the most broadly implemented and functioning health Information Technology (IT) system in the world today.</p> <p>8.5 million veterans' records accessible anywhere in the U.S.</p> <p>Vista includes a summary record immediately accessible for each veteran.</p> <p>Summaries can be tailored to meet specific care and/or provider needs.</p> <p>Appendix A of the user manual (see URLs) details all potential data groups that can be included on a provider-selected basis in any given summary.</p>
United States	AHIMA Publications on Personal Health Records (2003, 2005)	<p>American Health Information Management Association (AHIMA)</p> <p>— Personal Health Record (PHR) Work Group</p>	<p>i) <a href="http://www.myphr.com/">http://www.myphr.com/</a> - My Personal Health Record (public site)</p> <p>ii) (The Role of the PHR in the EHR (2005) — <a href="http://www.ahima.org/e-him/">http://www.ahima.org/e-him/</a> (scroll to reports)</p> <p><a href="http://library.ahima.org/xpedio/groups/public/documents/ahima/bok1_027539.hcsp?dDocName=bok1_027539">http://library.ahima.org/xpedio/groups/public/documents/ahima/bok1_027539.hcsp?dDocName=bok1_027539</a> (direct link to article)</p>	<p>In October 2003, AHIMA launched myPHR, a guide to understanding and managing personal health information for the general public. The site defines a health record, provides instructions on accessing health information and compiling and keeping a personal health record, and explains privacy rights.</p> <p>2005 WG recommendations included a minimum common dataset for inclusion in a PHR, included in Appendix A to the 2005 published article.</p> <p>A further publication in 2007, PHRs and Physician Practices, outlines the issues that physician practices encounter as patients increasingly utilize PHRs and explores development of practice policies and procedures needed to support patients who create their own PHRs.</p>



## 4 Key findings

The key findings from this scan have confirmed the determination of requirements for health summary records, as presented in ISO/TR 12773-1. The scan clearly showed that:

- initiatives cover the broad scope of business requirements for an HSR;
- initiatives address both of the primary use contexts — point-to-point provider communications and shared EHR context;
- there is a significant level of alignment with respect to the data groups deemed required for an HSR (USA, Canadian, Australian and European initiatives);
- the type/scope of data to be included in a given HSR data group varies across initiatives, ranging from all-inclusive to cover all primary use cases to common interest/common value data as the foundational HSR, plus sector/domain specific data extensions with/without customized forms/templates;
- the structures (content containers) for representing the HSR data vary depending on the standards and associated information models used to create the HSR; however, commonalities are evident (see ISO/TR 12773-1);
- the use of standards (coded data) has generally been kept to a minimum to account for the current realities of legacy systems and the variety of ways in which data is captured, as well as final decisions on adoption of national standards for recording and retrieving clinical information;
- there is little overlap between common interest/common value data found in HSRs and data found in specialized datasets targeted to specific health conditions and their data requirements, e.g. mental health; cancer care;
- identifying small sub-sets of specialty datasets for inclusion in a generic HSR or as optional extensions to a generic HSR will serve specific health sector needs better than an HSR that attempts to be all things for all providers;
- technical and clinical experts need to work together to contain the scope of HSRs to just that – a summary record;
- patient input to data collection is very helpful and a necessity.

## 5 Summary of initiatives

### 5.1 Overview

In this clause, several of the more widely known HSR initiatives as identified in Clause 3 are discussed in greater detail, including HSR implementations established or being piloted at the time of writing.

Single links/resources are referenced here. For a more detailed list of links/resources, see Clause 3.

Each summary includes some or all of the following sub-clauses:

- what it is (the nature of the initiative);
- purpose of the initiative;
- approach to development;
- basic architecture and structure;

- structured data (support for same);
- interoperability (whether the HSR supports/facilitates interoperability);
- adoption and implementation (current state);

Countries and initiatives covered in this clause include:

- Australia — NEHTA Data and Content Specifications
- Canada — COMPETE Study (Ontario); Core Data Set (Ontario); electronic Medical Summary (British Columbia); Medical Summary for Transfer of Patient Data (Alberta)
- European Commission — Report on the State of Developing Electronic Patient Summaries in European Union Member States and Beyond (2007)
- ISO — ISO 21549-3:2004, Health Informatics — Patient healthcard data — Limited clinical data
- United Kingdom — NHS England Summary Care Record; NHS Scotland Emergency Care Summary; NHS Wales Individual Health Record
- United States — ASTM CCR; HL7/ASTM CCD: HL7 CDA CRS; IHE Medical Summary Integration Profile; VISTa (US Veterans' Affairs Administration).

## Australia

### 5.2 National E-Health Transition Authority (NEHTA) (Australia) – Clinical data specifications and content specifications

<http://www.nehta.gov.au/> – NEHTA

[http://www.nehta.gov.au/index.php?option=com\\_content&task=view&id=235&Itemid=454](http://www.nehta.gov.au/index.php?option=com_content&task=view&id=235&Itemid=454) – NEHTA Data Group Library

[http://www.nehta.gov.au/index.php?option=com\\_content&task=view&id=139&Itemid=383](http://www.nehta.gov.au/index.php?option=com_content&task=view&id=139&Itemid=383) – NEHTA Standards Catalogue

#### 5.2.1 What it is

The National E-Health Transition Authority Ltd, in consultation with a broad range of stakeholders has developed specifications and recommended standards that support e-health. This includes a series of clinical data specifications intended for clinical communications and personal healthcare records. This includes specifications for particular health topics (i.e. foundation “data groups” such as “problem/diagnosis”, “clinical intervention”, and “adverse reactions”, “medication item”) and for structured clinical documents such as discharge summaries and referrals, which make use of the foundation data groups.

Data group specifications can be located in the National E-Health Data Group Library on the NEHTA website. They currently include immunization, medication, problem and diagnosis and adverse reaction. The NEHTA data specifications are detailed and comprehensive and include constraints on datatype, coded terms (where applicable) and others as defined.

Structured clinical document specifications have been developed for discharge summary and GP to specialist/acute care referral and can be found on the same site.

### 5.2.2 Purpose

The NEHTA specifications are aimed at standardizing the information structure and language used to name and describe clinical concepts, and providing the necessary contextual constraints to remove potential ambiguity in clinical statements. They represent the clinical information requirements for data collection and exchange to facilitate safe and effective continuity of care across different healthcare sectors, e.g. between acute care and general practice.

### 5.2.3 Basic architecture and structure

The metamodel is based on the ISO 11179 Metadata registries (MDR) International Standard and is used to provide a high level overview of a family of “care record summaries” which include the discharge summary.

Within this metamodel, clinical information is organized hierarchically into five levels:

- event summary;
- section;
- data group;
- data element;
- value domain.

An “event summary” is a collection of health information pertinent to a particular individual and is derived from a healthcare event that is relevant to the ongoing care of that individual. The event summary (which consists of a family of care record summaries) is composed of one or more data groups and/or possibly data elements, which are organized into section(s) (see 6.1 for reference). Examples of commonly used care record summaries include referral and hospital discharge.

A section is a “container” that organizes information in a way that is useful for healthcare providers and suited to the purpose for which the information was collected. It should also support safe re-use for secondary purposes. Additionally, a section provides a way to navigate through the data items thereby enabling more efficient querying.

A “data group” within a section is a composite data structure (a collection of data elements or smaller data groups) for holding related items of information. A data group “organizes” the data it holds. A data group can only be assigned values through the data elements that are contained within it. Examples of data groups are adverse reaction, alert and medication.

A “data element” is the smallest named unit of information in the model that can be assigned a value. The permissible values for a data element are constrained by a value domain. The same data element can be re-used in any number of data groups. For example, the “DateTime:Start” data element is used in the adverse reaction and the alert data groups. A data element may refer to different value domains depending on the context in which it is used.

### 5.2.4 Interoperability

One of NEHTA’s goals is to standardize the suite of priority care record summaries and their data content to achieve semantic interoperability amongst healthcare provider systems.

A second goal is to publish specifications in machine-readable formats that can be directly incorporated into systems and used by applications with minimal requirement for interpretation by software developers. This discharge summary specification represents a step towards that goal.

The data specifications have been designed to support full semantic interoperability. NEHTA's other interoperability standards (domain standards and interoperability framework) can be found on the NEHTA website, under the standards catalogue heading.

### 5.2.5 Adoption and implementation

The first NEHTA data groups were published in July 2005, initially as PDF documents. The National E-Health Data Group Library provides a browsable view of the specifications, downloadable PDF versions, separate UML class diagrams, and a zipped XML package.

The development of data specifications is an iterative process. These specifications are expected to evolve in response to changing healthcare practices, workflow and information requirements.

### 5.2.6 Hospital discharge summary specification

The discharge summary specification encompasses standard specifications for the content and structure of a typical discharge summary, and can be used in a range of clinical settings (e.g. an emergency department visit or an admission encounter) where relevant clinical information might be captured, stored, exchanged or displayed.

## Canada

### 5.3 COMPETE (Computerization of Medical Practices for the Enhancement of Therapeutic Effectiveness) – Ontario, Canada

<http://www.compete-study.com/>

[http://www.hc-sc.gc.ca/hcs-sss/pubs/chipp-ppics/2003-compete/index\\_e.html](http://www.hc-sc.gc.ca/hcs-sss/pubs/chipp-ppics/2003-compete/index_e.html)

#### 5.3.1 What it is

A series of COMPETE research projects have been conducted in Ontario, Canada by the Centre for Evaluation of Medicines, starting in 2001. COMPETE I investigated the impacts of EMR selection, implementation and level of use on physician, staff and patient work flow, satisfaction and quality of care. A core dataset was implemented as part of this project, based on earlier work by the Ontario Ministry of Health. The dataset was a summary of data deemed important to continuity of care. It was replicated from source EMR systems and stored in a central repository.

The COMPETE II project group developed and evaluated an integrated, web-based clinical decision-support tool for diabetes shared by patients and healthcare providers. A randomized controlled trial in family physician offices compared access to a diabetes tracker system versus usual care. The diabetes tracker was built using the core dataset as its foundation.

#### 5.3.2 Purpose

The core dataset was an extension of an earlier Ontario core dataset (Health Profile) initiative (see 5.4) with added data elements specific to chronic disease management and other research requirements. The specification can be found on the COMPETE study website. This was the first "live" implementation of a shareable EHR in Canada based on a health summary record generated and maintained in a central repository by primary care physicians.

COMPETE III, a similar study using a vascular tracker used a revised core dataset as well as HL7v3 messages developed by British Columbia's e-MS project (<http://www.e-ms.ca>).

### 5.3.3 Basic architecture and structure

COMPETE II supported an integrated EHR network model, through its foundation work on data standards, the implementation of a core dataset, XML data integration, vendor participation recruitment, clinical decision support development and evaluation, and maintenance of its frontline clinical users' network.

### 5.3.4 Structured data

Data captured in the COMPETE II core dataset included both structured and free text data in the following categories:

- referrals (date, to whom, result) (similar to the ASTM CCR specification);
- physical examination findings (vital signs, other assessments related to diabetes complications, and measurements specific to diabetes management e.g. blood sugars) (similar to CCR Vital Signs and Physiologic Measurements data group);
- hospitalization (when, where, for what) (similar to CCR Care Documentation encounter summary).

COMPETE II demonstrated the need for a structured but simple core dataset to support chronic disease management. However, the process of integration was very complex and costly. Technical and clinical experts needed to work together; patient input to data collection was very helpful and a necessity.

### 5.3.5 Current status

Key results and outcomes of all COMPETE studies to date have been published. Additional studies are planned.

## 5.4 Core dataset — Ontario Clinical Management System (sponsored by OntarioMD), Ontario, Canada

<http://www.ontariomd.ca> — click on CMS Standards link;

<http://www.skmtportal.cred.ca/search.aspx?artid=357>

### 5.4.1 What it is

Development of a primary care core dataset (CDS) (also referred to as a health profile), was initially proposed as part of Ontario's Primary Care Reform initiative in 1999. The intent was to allow primary care physicians to share essential patient information within their own sector and with other health professionals involved in the patient's care. An initial specification was created in 2003 but not released given primary care physician's low uptake of EMR systems at that time.

The initial CDS specification was revised and released in 2007 as part of an Ontario Clinical Management Systems specification (EMR system functional specification).

In essence, the CDS is a primary care provider summary record of important current and ongoing health problems, allergies, medications, past health history, surgery, etc.

### 5.4.2 Purpose

The revised CDS specification is intended for point-to-point data sharing – data export and import mapping schema from one EMR system to another to provide continuity of patient care, similar to the purpose of the Alberta Medical Summary for Transfer of Patient Data (see 5.6).

### 5.4.3 Basic architecture and structure

The business requirements and logical entity relationship diagram were developed using object oriented analysis techniques. A data model and a detailed specification have been developed for the core dataset.

### 5.4.4 Structured data

Coding is planned for many of the data elements although only a few have been assigned to date.

### 5.4.5 Interoperability

The initial focus for interoperability was system to system, e.g. source EMR systems and shared EHR systems; domain repository systems and shared EHR systems. Current focus is on point-to-point sharing from one EMR system to another.

### 5.4.6 Adoption and implementation

Implementation of the core dataset is dependent on implementation of computer systems in physicians' offices that will allow the physicians to create electronic medical records (EMRs) from which the core dataset is derived/extracted. Installation of these systems continues across Ontario.

Other health summary record (HSR) initiatives in Canada (BC, Alberta) have utilized the initial and revised Ontario specifications as source documents in developing their own HSR proposals and specifications.

Physiotherapists, chiropractors and other healthcare providers have all expressed interest in having access to and ultimately contributing to a shared core dataset. (See 6.2 for CDS data categories).

## 5.5 Electronic medical summary (e-MS) — British Columbia (BC), Canada

<http://www.e-ms.ca/>

### 5.5.1 What it is

Regional health authorities in southern British Columbia (led by the Vancouver Island Health Authority) have created a shareable dataset of patient information – the electronic medical summary (e-MS) to support continuity of care as well as emergency and after hours care.

This initiative came out of a recommendation from the BC Medical Association (BCMA). Project staff reviewed existing specifications e.g. ASTM Continuity of Care Record (CCR) (see 5.13) OntarioMD (Canada) core dataset (see 5.4) prior to developing its own dataset.

### 5.5.2 Purpose, interoperability

Project objectives were to:

- support shared care;
- develop standards and technology to enable data sharing and electronic medical record (EMR) interoperability;
- provide a “bridge” to integrate the variety of EMR systems used in physician’s offices;
- provide a “bridge” to integrate EMRs with EHR solutions.

### 5.5.3 Basic architecture and structure

The project was an early adopter of the HL7 CDA Release 2. The e-MS is an XML document with standard content and format. A CDA Implementation Guide has been developed, as well as an e-MS Exchange Protocol, message broker, web application and vendor integration. Detailed specifications and related documentation, implementation guides, etc. can be found on the e-MS website.

### 5.5.4 Adoption and implementation

Two pilots have been implemented, involving three regional health authorities and use of the e-MS in hospital emergency departments and for physicians on call. A third pilot was planned, using the e-MS as a community services referral standard. Based on the outcome of the pilots, the accepted e-MS standard will be integrated with the British Columbia provincial interoperable EHR strategy.

The e-MS has generated interest from other health authorities and projects in Canada as well as the HL7 standards community and Canada Health Infoway.

As a leader in standards development and providing integration/interoperability for EMR systems within physicians' offices, the VIHA's challenges include:

- lack of existing standards;
- being an early adopter of HL7 CDA Release 2;
- balancing CDA compliance and e-MS specific requirements;
- low uptake of technology in physician practices.

## 5.6 Medical Summary for Transfer of Patient Data – Physician Office System Program (POSP), Alberta, CA

[http://www.health.alberta.ca/about/HISCA\\_standards.html](http://www.health.alberta.ca/about/HISCA_standards.html) — look under Physician Office System

### 5.6.1 What it is

The Alberta Health Ministry decided not to define a minimum dataset (MDS) for Alberta's provincial shared EHR. Alberta's strategy is to build this dataset as various health sector stakeholders become ready to present a subset of clinical information from respective source systems associated with their domain area. This approach builds provider buy-in and trust that the information being shared is being defined in accordance with business needs. As each project/initiative is able to present a subset of data to the EHR, it must define this subset in accordance with access rules developed by a provincial EHR data stewardship committee and use defined data standards where they have been declared and approved by Alberta's provincial standards setting committee (Health Information Standards Committee of Alberta — HISCA).

The Medical Summary for Transfer of Patient Data is one such subset that has been approved by HISCA. Alberta has also defined datasets for drug histories and lab test results.

### 5.6.2 Purpose

The purpose of the Medical Summary for Transfer of Patient Data Project was to create a way in which an electronic summary of relevant patient information could be transferred from one physician office EMR system to another in order to support/facilitate informed care when a physician changes EMR vendors, e.g. physician moves, changes practices, changes vendor, e.g. physician choice, vendor not meeting requirements, goes out of business, etc.

Out-of-scope was an extension of the Medical Summary to encompass patient referral, defining the transmission of the data, or administrative issues such as how to arrange this information or how the information can be augmented with additional knowledge.

### 5.6.3 Basic architecture and structure

The structure is similar to other HSR models with a body, header and footer equivalent components.

Defined data elements include:

- structured data, including diagnosis, medications, allergies, test results, procedures, encounters and demographics;
- unstructured data, including journal entries, care plans, notes and unstructured messages.

The medical summary is intended to be independent of the technology used to perform the transfer.

### 5.6.4 Interoperability

The focus is point-to-point – EMR system to EMR system but potentially can be utilized for EMR system to shared EHR system transfers.

### 5.6.5 Adoption and implementation

A generic medical summary template and a core dataset straw model was developed and issued for wider consultation in Canada in June 2005. Standard definitions and codes are primarily HISCA standards. ICD-10-CA is used for diagnosis. (See 6.3 for Alberta's data categories; see their website for the detailed specification.)

## European Commission

### 5.7 Report on the State of Developing Electronic Patient Summaries in European Union Member States and Beyond (2007)

<http://www.ehealthnews.eu/content/view/605/62/> – European eHealth News Portal

This EC report analyses the current state of developing electronic patient summaries in European Union Member States and beyond. It highlights the benefits of such summaries and also the difficulties that need to be overcome to make use of patient summaries in different countries.

The report reached the following conclusions:

- The concept (of an electronic patient summary) is not yet unique and stable, thus the features of the summaries largely depend on the eHealth programme in which they are embedded.
- Overall scenarios for deployment depend on strategic decisions in each national and regional jurisdiction, which in turn, influence the format and the usage of clinical documents.
- A precondition is the deployment of suitable infrastructures, to identify citizens and professionals, to make available repositories and registries for the management of clinical documents across healthcare facilities, and to apply confidentiality measures.
- Further investigations should compare the scenarios in which the summaries are deployed within each jurisdiction, including the functions and the internal structure for the summaries.

## ISO

### 5.8 ISO 21549-3:2004 Health informatics — Patient healthcard data — Part 3: Limited clinical data

[http://www.iso.org/iso/iso\\_catalogue/catalogue\\_tc/catalogue\\_detail.htm?csnumber=34600](http://www.iso.org/iso/iso_catalogue/catalogue_tc/catalogue_detail.htm?csnumber=34600)



### 5.8.1 What it is

ISO 21549-3 includes data structures and definitions for a limited clinical dataset that provides a core set of essential health information intended to expedite care and diagnosis, support clinical decision-making and improve the quality of care. An extended dataset (ISO 21549-4) is an optional add-on and offers the ability to use the card for referrals and other aspects of continuity of care (versus the emergency care focus for the limited clinical dataset).

NOTE ISO initiatives pertinent to patient record summaries are primarily being undertaken by ISO/TC 215 WG 5 (Patient healthcards) in collaboration with CEN/TC 251 under the Vienna agreement. This WG is responsible for the development of an eight- (8) part standard for patient healthcards, intended to be used as portable patient health records throughout the European Union countries.

### 5.8.2 Purpose

The data contained on the card are intended to aid the delivery of emergency care, but on their own, are neither intended, nor fit for purpose to provide the total information required for the delivery of emergency care.

Clinical data may include items that provide information about health and health events, their appraisal and labelling by a healthcare provider and related actions planned, requested or performed. This includes data normally communicated by patient-carried warning cards and “Medic Alert” tokens.

### 5.8.3 Basic architecture and structure

A set of basic data objects was designed to facilitate the storage of clinical data in a flexible structure, allowing for future application-specific enhancements. The tools consist of a generic data structure based on an object-oriented model represented as a UML class diagram.

It is possible to take the data objects and recombine them whilst preserving their context specific tags, and to define new objects, while still preserving interoperability. In addition to the capability of building complex aggregate data objects from simpler building blocks, ISO 21549-3 allows for associations between certain objects, so that information can be shared.

“High level” object modelling technique (OMT) has been applied with respect to the definition of healthcard data structures. This is because a data card essentially provides specific answers to definite queries while having at the same time a need to optimize the use of memory by avoiding redundancies.

ISO 21549-3 specifies the basic structure of the data contained within the data object, limited clinical data, but does not specify or mandate particular datasets for storage on devices. It describes and defines the limited clinical data objects used within or referenced by patient-held healthcards using UML, plain text and abstract syntax notation (ASN.1). The specification includes attribute name, data type, multiplicity, length and comments.

The limited clinical data object is specifically divided into three separate data objects:

- a limited emergency dataset;
- a blood grouping and transfusion record dataset;
- an immunizations received dataset.

Because of their groupings, each of these can have differing security settings including access rights as determined by the provisions contained within accessory attributes (data that determine authentication and authorization in particular).

The immunization record contained within immunization details is intended to provide a record of immunizations received and is deliberately separate from other coded clinical data in order that it can be attributed differing security status.

The blood group and transfusion record is intended to be a separate data object from the rest of the patient dataset in order that it be able to be attributed differing security privileges in the same fashion as the emergency and immunization record. It is intended to record, where known, the record person's blood group and carry data regarding any blood products they may have received.

#### 5.8.4 Support for structured data

The general principle in ISO 21549-3 is that it is not mandatory to use a particular coding scheme, unless specified, when such codes act as parameters. One example is the use of EN 23166 for country codes. When a coding scheme is exclusively specified, no alternative coding scheme is allowed. Any references to coding schemes not so specified may be modified in the future, independent of the rest of the standard.

#### 5.8.5 Interoperability

Portable information systems and stores are used to support a more mobile population, greater healthcare delivery in the community and at patients' homes, together with a growing demand for improved quality of ambulatory care. The functions of such devices are to carry and to transmit person-identifiable information between themselves and other systems. Therefore, during their operational lifetime, they may share information with many technological systems that differ greatly in their functions and capabilities.

The advent of remotely accessible databases and support systems has led to the development and use of patient identification devices that are also able to perform security functions and transmit digital signatures to remote systems via networks.

With the growing use of data cards for everyday healthcare delivery, the need for a standardized data format for interchange led to the development of ISO 21549.

In order to facilitate interoperability, whenever an application is built for use in the healthcare domain in compliance with ISO 21549-3, data items required for that application shall be drawn from the list of objects (some of which are extensible) provided in ISO 21549-3. These will be used in conjunction with other data defined in other parts of ISO 21549.

#### 5.8.6 Adoption and implementation

ISO 21549-3 was published in 2004. Various implementation initiatives are underway in several European countries.

**NOTE** In Canada, interest in this type of card, referred to as a Smart Card, has waned given the variety of issues which can impact the utility of the cards, e.g. card failure or loss; cost of readers and infrastructure required for personalizing and issuing cards; need to make the data on the card available to other clinical information systems and the resulting requirement for cryptography to authenticate devices, users and applications. Quebec ran a pilot project for several years using a Smart Card as an access control and consent management device and a storage device for emergency-related personal health information. The project was abandoned in 2004 for a variety of reasons, most notably lack of healthcare provider adoption. Card technology offers the promise of local data storage, robust access control and non-repudiation services. Many industries have evaluated and considered this technology in Canada in the last decade and have found it to be a very difficult business case to build. [Personal communication: Director of Privacy and Security Architecture, Canada Health Infoway, June 2004].

### UNITED KINGDOM

#### 5.9 NHS England

##### The NHS Care Records Service — Summary care record (SCR)

<http://www.connectingforhealth.nhs.uk/systemsandservices/nhscrs> — NHS Connecting for Health — Care Records Service

### 5.9.1 What it is

The NHS Care Records Service is creating an EHR for all of England's 50 million plus population. Each patient's electronic care record will include:

- a) the detailed care record comprising:
  - 1) the person's complete electronic records held on computers at local healthcare organizations where treatment is provided e.g. general practice (GP) clinic; hospital;
  - 2) elements of all electronic records relating to that person from other organizations;
- b) the summary care record (held on the spine – see description at the end of this section) comprising:
  - 1) essential elements of a person's electronic record, extracted from general practice notes;
  - 2) essential elements relating to that person from other organizations where they receive care;
- c) HealthSpace – a personal health organizer (personal health record) and protected link to their summary care record for every person who chooses to have one.

The spine is a national, central database where summary patient records are to be stored. When fully implemented, local records will automatically upload important information to the summary patient record on the spine. In addition to the summary record service, the spine includes a patient demographics service, choose and book service (to manage patient referrals to specialists and other clinical services), electronic prescription services, a transaction messaging service, a clinical spine application (to provide web-based access to the demographics and summary record information), a user directory service (authorized users; accredited systems and services), an access control framework and secondary uses service.

### 5.9.2 Approach — creation and maintenance of the summary care record

The summary care record (SCR) will be derived from the records of organizations delivering care to that person. There is a primary care physician (GP) component derived from the primary healthcare team's record. That practice will be responsible for the accuracy of that component of the summary. There may be components from several hospitals that the person attends, a mental health trust, a dental practice and so on. These components will in total be the SCR, with each organization responsible for maintaining its part. In each organization, the person's record will clearly indicate which items are included in that organization's contribution to the SCR. The spine will interface with all the local IT systems within the national programme and include links/pointers to information in local records.

The first NHS organizations to contribute to the SCR are general practices. The process will be similar in other organizations. As a clinical database becomes compliant<sup>1)</sup> and joins the NHS Care Records Service, and after its data quality has been validated, an extract from each person's record in that database will become part of the SCR. In addition to summary data on key events in a patient's life and care, the record will also include details of contacts with care providers (encounter history).

The extract for the SCR should contain:

- a) major diagnoses, problems and surgical procedures;
- b) allergies, interactions and adverse drug reactions;
- c) recent and current prescriptions;
- d) recent results of investigations.

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1) Compliance occurs when the organization is using an NPfIT (National Programme for Information Technology) supported programme and meets interoperability and hosting requirements.

Much of this information will come from the GP record. The inclusion of potentially sensitive mental health diagnoses, sexual health episodes or infections requires individual consideration by both the healthcare professional and the person for inclusion/exclusion in the SCR.

The record must accumulate new key items of the person's care as time goes by, losing other items as their relevance lapses. The SCR, even when used to support decisions, will not change the healthcare professional's own (local) record of the person's care, unless he/she chooses to include information from the SCR in their own records.

The range of information in the SCR must be carefully controlled in order for it to remain a summary record.

Normally each person's SCR will be available to a healthcare professional with role-based access and a reason to access (a legitimate relationship). Authorized access also requires that a smartcard and PIN number be issued by the person's NHS trust (general practice). Access will be with the person's implied consent.

People can choose to limit their participation in the SCR in the following ways:

- emergency only — their SCR is only accessible in an emergency;
- partial access — some information is withheld from the SCR at the patient's request (explicit consent) and a flag indicates that some data are missing (sealed envelope) — precisely how this will work is yet to be clarified. If it is considered that it might be important, the care professional can then ask the person to share the missing information with them and it will then be up to the person to agree or not;
- no SCR — they do not have an SCR and therefore no-one can access it, even in an emergency.

There will be limits to a person's ability to reduce their participation. They will not be able to restrict entries when to do so would put others in danger or put public health at risk, e.g. an accurate history of violence towards healthcare providers would be included regardless of the person's wishes.

Each person with an SCR will be able to see that record through HealthSpace or when attending their NHS organization. They can also apply formally for a copy as part of their rights under the Data Protection Act.

From 2008 people have had access to their SCR via a secure link using a website called HealthSpace. Using HealthSpace they will be able to look at their record and add comments to it.

### 5.9.3 Purpose

Having each patient's SCR stored on the spine will mean that wherever and whenever a patient seeks care from the NHS in England, those treating them will have secure access to summary information to assist with diagnosis and care. The summary record will also point clinicians to where full local records are held.

The spine will also provide a secondary uses service (SUS), using anonymized data for business reports and statistics for research and planning purposes. This includes looking at public health trends, analysing the effectiveness of treatments and planning the number of beds and staff the NHS needs.

### 5.9.4 Support for structured data

All coded entries to the SCR will be transmitted and recorded as SNOMED CT codes (as will all entries in the NHS care record service in time). The SCR can also be used by a healthcare professional to record some free text e.g. the range of agencies involved in delivering care to that person.

### 5.9.5 Adoption and implementation

Several early adopter programmes are underway in England. As a first step, allergies, current prescriptions and any previous adverse reactions to medication will be available to providers treating patients in a range of

locations e.g. emergency departments; after hours/out-of-hours clinics. The SCR is expected to roll out nationally in 2009/10 on a region-by-region basis.

### 5.10 NHS Scotland – Emergency care summary (ECS)

[http://www.nhs.uk/supplementary\\_pages/news\\_detail.php?newsid=60](http://www.nhs.uk/supplementary_pages/news_detail.php?newsid=60) – NHS Scotland's Emergency Care Summary

The ECS is an extract of data from primary care practice computer systems (practice EHRs) sent to an electronic store from where it can be viewed by clinicians working in out-of-hours organizations. All Scottish practices were connected by the end of 2007 with over 5 million records stored for the entire population of Scotland.

Patients can opt out of the ECS by informing their practice. Every patient is asked for their consent for the clinician to view their information when seen after hours or when contacting the 24 h helpline. Practices can check whether their own patients' records have been viewed. From the moment a flag is set against the patient's computer record, clinical data will be removed from the ECS store and a message will be displayed stating that 'patient consent has been withheld'. This applies to ALL data, including historic data and telephone numbers.

The Royal College of General Practitioners (RCGP) of Scotland recommended that the ECS hold the following categories of data:

- drugs, allergies and adverse drug reactions: automated process;
- GP summary from local system: semi-automated process – requires patient's explicit consent, e.g. significant current and past medical problems, procedures and treatments(s);
- patient preferences (limited set): manual process e.g. advance directives; refusal of treatment for religious reasons.

The RCGP also recommended that the ECS must have the following attributes:

- accuracy;
- completeness;
- timeliness (up to date);
- safety (requires all of the above attributes plus understanding of issues relating to meaning and context);
- relevance (includes context);
- consistency (information in the record should be internally consistent i.e. medication lists and clinical problems and diagnoses should be compatible);
- appropriateness (any information, especially relating to third parties or family members should not contain any personal data that could breach relevant privacy guidelines).

### 5.11 NHS Wales – Individual health record

<http://www.wales.nhs.uk/ihc/home.cfm> — Informing Healthcare, NHS Wales

This initiative is similar to the emergency care summary in Scotland. It was successfully piloted in a large number of GP practices in one geographic area of Wales during 2007. It allows patient information held on GP practice computer systems (practice EHR systems) to be viewed by on-call medical staff. This improves the safety and quality of care outside hours by ensuring the most appropriate treatment is given, based on knowledge of the patient's medical history.

The individual health record in out-of-hours care holds details of the individual's medication, allergies, current problems and diagnoses. Its aim is to ensure the clinicians on duty have vital information when it is needed most.

A survey of clinicians working at the pilot region 24 h out-of-hours call service showed that more than 70 % felt the record helped them provide tailored advice to callers. When dealing with older patients, or those with chronic conditions, this rose to 80 %.

The project evaluation shows that the individual health record is also helping out-of-hours GPs reduce the number of callers referred to emergency departments or for hospital admission. A nurse or physician will ask patients for their consent on each occasion before they access the patient's record. By spring 2008, more than 800,000 patients were covered. Roll-out to the rest of Wales (population approximately 3 million) will occur incrementally.

## United States

### 5.12 Care record summary – Implementation guide for HL7 CDA Release 2 – Levels 1 and 2 (US Realm)

Care Record Summary Level 1 IG (2005) & Care Record Summary Level 2 IG (2005)

<http://www.hl7.org/documentcenter/ballots/2005may/downloads/CDACareRecordSummaryIGLevel1.zip>

<http://www.hl7.org/documentcenter/ballots/2005may/downloads/CDACareRecordSummaryIGLevel2.zip>

— HL7 CDA Resource Page — <http://hl7book.net/index.php?title=CDA>

— US Realm CDA Implementation Guide, R2, Care Record Summary June 2006  
<http://www.hl7.org/search/search.cfm>

#### 5.12.1 What it is

The first HL7-balloted implementation guide (IG) for CDA Release 2.0 was for care record summary (CRS) documents levels 1 and 2. The intent was to establish a format and process for defining constraints on 1) clinical content and 2) the encoding of that content. The guides include sample CDA R2 documents, schema, vocabulary data e.g. HL7, LOINC, SNOMED-CT and rendering style sheets.

The summary of care document domain was chosen for the implementation guide because internationally, this type of document is the most common first area of application for the CDA. This guide is designed for the US. There are similar national and regional CDA implementations in Germany, Finland, Greece, Canada, Japan and other locations.

#### 5.12.2 Purpose

A care record summary document contains a patient's relevant health history for some time period. It is intended for communication between healthcare providers. It applies to discharge summaries, transfer summaries and similar types of summary documents. The CRS prescribes the content that is common for every in-patient stay or transfer of care. Similar content is required for hospital accreditation in the US.

#### 5.12.3 Approach

The IG defines required and optional sections and specifies information expected of content. The development of this specification was based on a review of existing draft and final specifications or IGs for similar artefacts in the US and international realms e.g. JCHAO; British Columbia (Canada) electronic-medical summary (e-MS), sample documents and common practices. This was coupled with a domain expert review of CDA header and body elements and attributes. (See Clause 6).

The IG specifies two levels of conformance requirements — Level 1 specifies constraints upon the CDA header and the content of the document. Level 2 specifies constraints upon the structured body. Out-of-scope are specifications of workflows, messages or procedures used to negotiate the transfer of care or referral.

A final US Realm version was published in 2006.

Next steps underway/planned include:

- development of CRS levels 1 and 2 implementation profiles in collaboration with IHE;
- development of CRS Implementation guides with field-level data (CDA level 3) in collaboration with the HL7 Patient Care Technical Committee;
- discussions with HL7 affiliates on internationalization of the care record summary.

#### 5.12.4 Adoption and implementation

HL7 US tested a health summary record standard throughout 2005, which was proven to meet the requirements of at least six different health and medical domains (mother and childcare, juvenile care, stroke patients, cardiology, home care and chronic disease). [Personal communication: William Goossens]. The Netherlands initiated a similar project for record exchange with fully structured data. In Canada, the Western Health Information Collaborative (WHIC) is working with these models for chronic disease management.

### 5.13 Continuity of care record E2369 – Specification – ASTM

<http://www.astm.org/> — search for publication E2369

#### 5.13.1 What it is

The CCR is a standard specification, published in January 2006 and developed over a three year period as a collaborative effort led by ASTM International in conjunction with eleven sponsoring organizations, including the Massachusetts Medical Society, the Healthcare Information Management and Systems Society (HIMSS), the American Academies of Family Physicians and Paediatrics, and the American Medical Association.

The CCR is an outgrowth of the three page NCR-based Patient Care Referral Form designed and mandated by the Massachusetts Department of Public Health for use primarily in in-patient settings. This form has been in widespread use for many years in Massachusetts. Other minimal datasets, both electronic and paper-based, were also utilized in developing the CCR.

#### 5.13.2 Purpose

To provide a point-in-time view (snapshot) of a patient's health history for point-to-point communication between providers, especially those in office settings, to support clinical decision-making, improve quality, continuity and efficiency of care and reduce medical errors. It also provides the patient with a means of direct access to their relevant health history.

#### 5.13.3 Basic architecture and structure

A detailed specification and XML schema was developed. Because it is expressed in XML, the CCR can be created, read and interpreted and imported/exported by various EHRs from various software companies, displayed in a variety of formats e.g. HL7 messages, viewed within any of the popular web browsers and printed out in user-friendly paper formats e.g. Word. The CCR maps to and from any data format with a simplified set of data parsers and translators (XML/XSLT). Data feeds can be real-time or batch.

The CCR consists of three core components:

- header — sections (identifiers, purpose);
- body — sections (health history, medication, immunizations, problems);
- footer — sections (providers, references, comments, signatures).

Within these sections, data are intended to be expressed in as much detail as possible. The CCR is an XML document object constructed from a set of discrete XML building blocks that are defined as data objects contained within sections. Each discrete medication, problem etc. within a section represents a discrete data object. The information model for the CCR is the CCR data elements spreadsheet, a defined set of core data in specified XML code (see 6.5).

### 5.13.4 Support for structured data

Detailed coding is recommended whenever practical within the CCR. In all instances, the coding system and version must be specified<sup>2)</sup>. The CCR Work Group suggested the following coding (non-normative).

- Problems coded at the highest level using SNOMED CT and the most recent ICD codes at the time the CCR is generated to accommodate the need for various healthcare entities interacting with the CCR data to have accurate coding for reimbursement purposes. These and other controlled vocabularies are integral to the enhancement of data to support intelligent clinical decision support.
- Procedures coded at the highest level using relevant SNOMED CT, LOINC and CPT (current procedural terminology) codes at the time the CCR is generated.

### 5.13.5 Interoperability

The CCR is designed to support incremental interoperability towards full semantic interoperability by promoting highly structured and coded information to support data exchange and complex data expression as well as both human and automated clinical decision support, through the use of alerts, reminders, performance measures and sophisticated data analysis.

Using the required XML schema or other XML schemas authorized through joint efforts of ASTM and other standards development organizations, it is expected that properly designed EHR systems will be able to import and export all CCR data to enable automated healthcare information transmission with minimal workflow disruption. Equally important, it will allow the interchange of the CCR data between otherwise incompatible EHR systems.

The schema allows data from any entity to be exchanged securely with any other authorized entity that supports the CCR structure and function as outlined within the implementation guide.

Due to lack of any comprehensive and widely used clinical content standards for patient summaries in healthcare, most systems are not standardized or interoperable, and their capabilities relative to structuring data vary widely. In order to deal with this reality, the CCR XML has been designed to allow expression of data in a range of modalities:

- non-specific text strings;
- coded text strings;
- coded or uncoded text strings with an arbitrary level of structure;
- fully structured and coded data expression.

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2) While it is recognized that there is no clear method to interpret the relationship between coded elements, it is outside the scope of this part of ISO/TR 12773 to resolve this difficulty.



### 5.13.6 Adoption and implementation

The CCR has significant momentum and support due to the leadership of ASTM International and the co-sponsorship of major U.S. associations representing thousands of healthcare providers and other professionals. There are a number of CCR-based data mapping and deployment projects underway in the U.S. The American Academy of Family Physicians, through their Centre for Health Information Technology <http://www.centerforhit.org/x11.xml> promotes adoption and deployment of field-capable CCR-compatible software applications and tools, and acceleration of integration of the CCR into existing EHR software.

Up-to-date information can be found at <http://www.ccrstandard.com/> – The CCR Standard Resource site.

## 5.14 Continuity of care document (CCD) – HL7/ASTM

### 5.14.1 What it is

Development of the HL7 continuity of care document (CCD) represents the joint efforts of HL7 and ASTM International. It describes how to implement the continuity of care record (CCR) dataset with the standard architecture for clinical records developed by HL7 — the clinical document architecture (CDA).

### 5.14.2 Purpose

The CCD describes the use of the CCR standard dataset so it can function within the broader capabilities of HL7's CDA. Improved patient care was the driving priority. CCD harmonizes the two separate standards by using CCR within the broader context of CDA. It shares summary information about the patient in an easy-to-read format, using CCD templates to constrain the data. The information can be read by the human eye or processed by a machine (such as an EHR system), and can be sent electronically or manually carried by the patient.

### 5.14.3 Adoption and implementation

The CCD was approved for publication as a result of successful HL7 balloting in January 2007.

The CCD specification contains U.S. specific requirements; its use is therefore limited to the U.S. The U.S. Healthcare Information Technology Standards Panel has selected the CCD as one of its standards.

The U.S. Certification Commission for Healthcare Information Technology (CCHIT) <http://www.cchit.org/> certification criteria (2008) require all ambulatory and inpatient EHRs to be CCD compatible, making CCD the preferred standard for clinical document exchange moving forward in the U.S. The criteria are also instrumental in encouraging the use of EHRs within the healthcare community.

## 5.15 Medical Summary Integration Profile and Medical Summary Content Specification IHE — Integrating the Healthcare Enterprise

[http://www.ihe.net/Technical\\_Framework/index.cfm#pcc](http://www.ihe.net/Technical_Framework/index.cfm#pcc)

[http://wiki.ihe.net/index.php?title=Medical\\_Summaries\\_Profile](http://wiki.ihe.net/index.php?title=Medical_Summaries_Profile)

NOTE Integrating the Healthcare Enterprise (IHE) is a not-for-profit initiative that was founded in 1998 in the USA by the Radiological Society of North America (RSNA) and the Healthcare Information and Management Systems Society (HIMSS). It is now international in scope with established organizations in Canada, Europe and Asia.

### 5.15.1 What it is

Introduced in 2005, the first version of the IHE Patient Care Coordination Technical Framework specified the Medical Summary Integration Profile, including the Medical Summary Content specification. In subsequent years, additional profiles were added e.g. Emergency Department Referrals (EDR). IHE integration profiles offer a common language that healthcare professionals and vendors may use in communicating requirements for the integration of products. IHE transactions are interactions between actors (information systems or components) that transfer the required information through standards-based messages.

The integration profile and content specifications provide a mechanism to automate the sharing process between care providers for a variety of medical summaries. These are a class of clinical documents that contain the most relevant portions of information about the patient intended for a specific provider or a broad range of potential providers in different settings.

Standards for the content of the Medical Summary profile are based on the HL7 Clinical Document Architecture, Release 2.0 (CDA R2), the Care Record Summary Implementation Guide for CDA R2 — Levels 1 and 2 (US Realm), and the ASTM/HL7 Continuity of Care Document Implementation Guide.

### 5.15.2 Purpose

Medical Summaries are usually created and accessed at points in time of transfers of care such as referrals or discharges. These profiles have been identified as critical to improving continuity of care. A trial implementation version was finalized in September 2007.

With respect to content, the profiles define a minimum set of “data elements” that should be forwarded or made available to subsequent care provider(s) during specific transfer of care scenarios, e.g., for discharge, or referral to a specialist. In addition, they define the utilization requirements/options for the receiver in order to ensure that the “care context” of the sender is appropriately maintained following the information transfer.

### 5.15.3 Interoperability

<http://www.ihe.net/Connectathon/index.cfm>

IHE provides a detailed implementation and testing process to promote the adoption of standards-based interoperability by vendors and users of healthcare information systems. The process culminates in the Connectathon, a week-long interoperability-testing event. These events are held annually in North America and Europe. Multiple vendors and systems conduct cross-platform tests of interoperability. Vendors have to repeat each test with at least three other companies to prove true interoperability.

Testing of the Medical Summary Integration Profile requires the vendor receiving the information to be able to view the document, import and store the document for later viewing, and import specific patient information such as test results or medication lists.

### 5.15.4 Adoption and implementation

IHE is strongly supported by industry: More than 220 companies have developed IHE compliant systems between 1999 and 2007 and participated in IHE Connectathons. There has been significant interest in IHE's cross-document sharing profiles such as the Medical Summaries Profile, both from the commercial side and from national EHR projects such as Canada Health Infoway, which has resulted in a successful market uptake.

## 5.16 VistA — United States Veterans' Health Administration

<http://www.va.gov/vdl/application.asp?appid=63> — VHA Software Document Library — Computerized Patient Record System (CPRS) — Health summary technical and user manuals.

The most broadly implemented and functioning health Information Technology (IT) system in the world today is that of the VHA. The clinical computer system, known as Veterans Health Information Systems and Technology Architecture (VistA), covers more than 1 200 sites of care, including acute care hospitals, ambulatory facilities, skilled nursing facilities, and pharmacies. The system contains a single health record on 8,5 million veterans (25 million eligible) in 22 regions across the United States. Authorized clinicians have access to any veteran's record, regardless of which region they reside in.

The comprehensive cover sheet displays timely, patient-centric information, including active problems, allergies, current medication, recent laboratory results, vital signs, hospitalization and out-patient clinic history. This information is displayed immediately when a patient is selected and provides an accurate overview of the patient's historical and current status before clinical interventions are ordered. The system also allows the user to create different types of health summary records tailored to a particular clinical requirement or referral/transfer situation.

A HealtheVet pilot project is underway which includes a Personal Health Record (similar to the NHS HealthSpace initiative) feature that will let veterans personalize their health data using new journals and electronic logs, which become their private and secure information. The e-logs will let veterans track readings for indicators such as blood sugar, blood pressure, cholesterol and heart rate. It provides veterans with a safe, secure, and private electronic copy of their own VA health information through an Internet web environment. This health information is stored in a secure and private environment called an eVault where all the data are encrypted.

## 6 Sample health summary records — overview of data groups, specifications for structure, content as applicable

NOTE HSR datasets included in this section are listed alphabetically by country of origin.

### 6.1 Australia — National E-Health Transition Authority (NEHTA)

Detailed specifications for data and content standards (discharge summary, referral) can be found at:

[http://www.nehta.gov.au/index.php?option=com\\_content&task=view&id=235&Itemid=454](http://www.nehta.gov.au/index.php?option=com_content&task=view&id=235&Itemid=454) — Data Group Library.

### 6.2 Canada — Core Dataset — OntarioMD

Details of the data to be captured under each category can be found at:

<http://www.cred.ca/skmt/docs/attachments/357/CMS%20Specificationv2%200%20April%2016%202007.pdf> or at

<http://www.ontariomd.ca> – click CMS Standards link – see Appendix 1 for Core Data Set detailed specification

A notes field is available in each category, to allow the provider to add optional information in free-form text format. If structured data are not yet available in the EMR system for a particular category, data can initially be sent in free-form text format to the relevant notes field.

### 6.3 Canada — Medical Summary for Transfer of Patient Data (Alberta)

[http://www.health.alberta.ca/about/HISCA\\_POSSP\\_xferPatData.pdf](http://www.health.alberta.ca/about/HISCA_POSSP_xferPatData.pdf)

- Document sender; document receiver; patient record; patient identifier; patient location; provider-physician information; patient emergency contact
- Alert
- Device
- Developmental history
- Reproductive history
- Social history
- Family history
- Quantitative observation
- Allergy
- Encounter
- Immunization
- Condition (diagnosis) (problem)
- Medical laboratory results
- Medication
- Plan of care
- Procedure
- Attachments

#### 6.4 Canada — Electronic medical summary (British Columbia)

<http://www.e-ms.ca/> – detailed specification and related artefacts posted

Demographic data: name; address; telephone; patient identifiers; emergency contact.

Clinical data:

- alerts and allergies
- active problem list
- labs
- medical history
- surgical history
- observations
- medications

Other data: other providers(s); referral reason; attachments.

#### 6.5 United States — ASTM Continuity of Care Record

The detailed specification is available at: <http://www.astm.org> - search publications for publication E2369.

Header — defines the document parameters, including its unique identifier, language, version, date/time created, the patient whose data it contains (includes a patient identifier), the sender, the recipient and purpose of the CCR. There is no unique identifier – identifiers are based on a distributed system with ID generated by the system that generated the CCR.

Body — contains the core patient-specific data: (administration, clinical sections)

- Insurance
- Support (providers, contacts)
- Functional status
- Problems
- Family history
- Social history
- Alerts
- Medications
- Medical equipment
- Advance directives
- Immunizations
- Vital signs
- Results
- Procedures
- Encounters
- Plan of care
- Practitioners

Footer — contains sections defining all of the actors, as well as information about external references, all text comments, and signatures associated with any data within the CCR.

## 6.6 United States — IHE Content Profiles

[http://www.ihe.net/Technical\\_Framework/index.cfm#pcc](http://www.ihe.net/Technical_Framework/index.cfm#pcc)

Patient Care Coordination Technical Frameworks

NOTE Additional profiles are in development.

Tables 2 and 3 summarise the medical record entries for the relevant sections in the HL7 CDA Care Record Summary for a referral summary content profile and a discharge summary content profile.

**Table 2 — Referral summary content profile**

Use case document section	CRS restriction	CRS category
Reason for referral	R	Reason for referral
History present illness	R	History of present illness
Active problems	R	Conditions [problem list]
Current meds	R	Medications [history of medication use]
Allergies (and other adverse reactions)	R	Allergies and adverse reactions
Resolved problems	R2	Conditions [history of past illness]
List of surgeries	R2	Past surgical history
Immunizations	R2	Immunizations
Family history	R2	Family history
Social history	R2	Social history
Pertinent review of systems	O	Review of systems
vital signs	R2	Physical exam [vital signs, physical findings]
Physical exam	R2	Physical exam [general status, physical findings]
Relevant surgical procedures/clinical reports (including links)	R2	Studies and reports
Relevant diagnostic test and reports (lab, imaging, EKG's, etc.) including links.	R2	Studies and reports
Plan of care (new meds or interim referrals like physical therapy, labs, or X-rays ordered)	R2	Care plan
Advance directives	R2	Advance directives
Patient administrative identifiers	R	Header
Pertinent Insurance information	R2	Header [participant]
Data needed for state and local referral forms, if different than above	R2	Possible solutions include Section extensions, external links, additional constraints — TBD

R = Required; R2 = Required if data available; O = Optional.

Table 3 — Discharge summary content profile

Document section	CRS restriction	CRS category
Date of discharge	R	Header [effectiveTime]
Participating providers and roles	R	Header [participants]
Discharge disposition (including who, how, where)	R	Care plan
Admitting diagnosis	R	Conditions [hospital admission diagnosis]
History of present illness	R2	History of present illness
Hospital course	R	Hospital course
Discharge diagnosis (including active and resolved problems)	R	Conditions [hospital discharge diagnosis]
Selected medicine administered during Hospitalization	R2	Medications [history of medication use]
discharge medications	R	Medications [hospital discharge medications]
Allergies and adverse reactions	R	Allergies and adverse reactions
Discharge diet	O	Optionally found in care plan
Review of systems	O	Review of systems
Vital signs (most recent, high/low/average)	R2	Physical exam [vital signs, physical findings]
Functional status	O	Functional status
Relevant procedures and reports (including links)	R	Studies and reports
Relevant diagnostic tests and reports (including links)	R	Studies and reports
Plan of care	R	Care plan
Administrative identifiers	R	Header
Pertinent insurance information	O	Header

R = Required; R2 = Required if data available; O = Optional.

## 6.7 United States — HL7 CDA Care Record Summary Implementation Guide Levels 1 and 2 2006 — Required and optional sections of a CRS (US Realm)

### Header — Required sections

- document and document type identifiers, applicable time data (e.g. document effective time, document author);
- assigned healthcare provider(s);
- record custodian, document legal authenticator;
- service and encounter types and date ranges as appropriate;
- all persons named along with roles, participations, participation date ranges, identifiers, address and telecom information;
- all organizations named along with roles, participations, participation date ranges, identifiers, address and telecom information;

- record target (the patient whose health history is described in the CRS) data e.g. patient's birth date, gender;
- insurance and other guarantor information as appropriate.

**Body — Required sections: (align with both the NEHTA and the CCR Clinical Information Data Groups)**

- Conditions:
  - problem list (active, none, unknown )(R); resolved (O);
  - history of past illness;
  - diagnoses — admission, discharge;
  - allergies and adverse reactions — history of allergies (known, none, unknown, removed from list);
  - history of medication allergies (O) — pharmacy, dietary, general;
  - medications — history of medication use, admission and discharge meds (O);
  - hospital course (O).
- Optional sections:
  - reason for visit/chief complaint      — past surgical history (relevant procedures);
  - reason for referral                      — prior encounters;
  - history of present illness              — family history;
  - advance directives                      — social history;
  - functional status                        — immunizations;
  - review of systems                        — care plan;
  - physical exam (includes vital signs — height, weight, temperature, BP, pulse rate, respiratory rate, O<sub>2</sub> saturation; foetal vital signs);
  - studies and reports (includes lab results).

**6.8 United States — Personal Health Record — Minimum Common Dataset — AHIMA**

Details of the data elements for each data group can be found in the article “The Role of the PHR in the EHR”, Appendix B at:

[http://library.ahima.org/xpedio/groups/public/documents/ahima/bok1\\_027539.hcsp?dDocName=bok1\\_027539](http://library.ahima.org/xpedio/groups/public/documents/ahima/bok1_027539.hcsp?dDocName=bok1_027539)

Suggested common data groups include:

- personal demographic information;      — surgery;
- general medical information;              — medication;
- allergies and drug sensitivities;          — immunizations;

- conditions;
- hospitalization;
- clinical tests;
- pregnancy history.

## 6.9 ISO 21549-3, Health informatics — Patient healthcard data — Part 3: Limited clinical data

### Limited emergency dataset

- Asthma
- Heart disease
- Cardiovascular disease
- Epilepsy (fits)
- Neurological disorder
- Coagulation disorder
- Diabetes
- Taking: antipsychotic medication; anticonvulsants; anti-arrhythmics; blood pressure drugs; anticoagulants; anti-diabetic agents; antihistamines
- Received streptokinase
- Allergic to: analgesics; animal hair; antibiotics; citrus fruits; house dust; eggs; fish/shellfish; iodine; milk; nuts; pollens; other agent
- Other data
- Accessory attributes
- Glaucoma
- Dialysis treatment
- Transplanted organ
- Missing organ
- Removable prosthesis
- Pacemaker *in situ*
- Slow acetylator

### Immunization dataset

- Attribute name
- Immunizations received (class)
- Attribute names:
- Immunization indicator (enumerated)
- Immunization status (enumerated)
- Last date immunized (date)
- Immunization code (coded data)
- Accessory attributes



**Blood group and transfusion dataset**

- Blood grouping
- Blood group
- Rhesus factor
- Date last blood grouping
- Blood group free text
- Blood transfusion details
- Blood transfusion indicator
- Last blood transfusion date
- Blood product given (coded)
- Accessory attributes

**6.10 NHS UK — Scotland – Emergency Care Summary (ECS)**

The ECS contains the following data categories (groups):

- patient demographics (unique identifier, forename, surname, previous surname, address and postcode, telephone number(s), date of birth, sex, current GP practice, seen by GP);
- allergies and adverse reactions;
- medications (drug name, dose, quantity, date prescribed);
- acute prescriptions information from the last 30 d;
- repeat prescription information that is current (drug name, dose, quantity, date prescribed);
- consent status;
- registration status;
- deducted field (indicating that the patient is no longer registered at the practice).

## Acronym index

ASN	Abstract syntax notation
BC	British Columbia
CCD	Continuity of care document
CCR	Continuity of care record
CDA	Clinical document architecture
CDA R2	Clinical document architecture, release 2.0
CDS	Core dataset
COMPETE	Computerization of medical practices for the enhancement of therapeutic effectiveness
CRS	Care record summary
ECS	Emergency care summary
EHR	Electronic health record
GP	General practice; General practitioner
HIMSS	Healthcare Information and Management Systems Society
HISCA	Health Information Standards Committee of Alberta
HSR	Health summary record
ICEHR	Integrated care electronic health record
IG	Implementation guide
IHE	Integrating the Healthcare Enterprise
NEHTA	National E-health Transition Authority
PCP	Primary care provider (or physician)
PHR	Personal health record
POSP	Physician office system programme
RIM	Reference information model
SCR	Summary care record
VistA	Veterans' Health Information Systems and Technology architecture
XML	Extensible mark-up language

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