BOUNDARY INFOSTRUCTURES FOR CHRONIC DISEASE

by

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DEDICATION

In memory of

GEORGE ALAN PATERSON,

beloved husband and father to Sheila, John and David

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ABSTRACT

An exchange of electronic health resources among users from different communities of practice that is mediated by boundary objects is made more meaningful and interoperable than one that is not. Boundary objects are objects that are flexible enough to be used in more than one context and to communicate between contexts, such as those depicted in the CHAMP Community of Learners model (clinicians, health informaticians, administrators, medical educators, patients). Boundary infostructures are built from networks of boundary objects.

Two types of boundary objects are used to construct the boundary infostructures for chronic disease: methods of common communication and repositories. The methods are terminology systems (ICD-9, ICD-10-CA, CCP, CCI, Primary Renal Diagnosis, SNOMED 3.5, SNOMED CT, ATC, UMLS) and information architecture standards (HL7 Clinical Document Architecture and topic maps). The Clinical Document Repository is formed from Nova Scotian and Quebec hospital records for patients with chronic kidney disease, diabetes and hypertension (ICD-10-CA codes N18.9, E11.22 and I12, or SNOMED codes D3-02000, DB-61030 and DB-63130 plus ICD-9/9-CM codes 250.30/250.40 and 403.91/403.91). The Patient Information Repository is constructed from texts in a patient portal for inflammatory bowel disease patients (ICD-10-CA codes K50-K52). The two repositories are used for semantic interoperability and completeness evaluations.

This exploratory research examines how semantic interoperability among electronic health resources is enabled by a boundary infostructure. The goal is to increase the semantic interoperability of electronic health resources through a boundary infostructure designed to improve the pragmatic proficiency of authors and the pragmatic competency of learners. The thesis explores the question: How might the creation of a boundary infostructure bridge perspectival differences among communities of practice and produce electronic health resources that are more semantically interoperable than those produced by current infostructures?

LIST OF ABBREVIATIONS AND SYMBOLS USED

A1C: glycosylated hemoglobin

Abd: abdomen

ALP: alkaline phosphate

ALT: alanine aminotransferase

ANA: antinuclear antibody

ANCA: antinutrophil cytoplasmic antibody

Anti-DNA: anti-deoxyribonucleic acid

Anti-GBM antibody: anti-glomerular basement membrane antibody

Anti-MPO: anti myeloperoxidase

Anti-PR3: anti-proteinase-3

ASA: aspirin

AST: aspartate aminotransferase

ATC: Anatomical Therapeutic Chemical

BID: twice daily

Bili: bilirubin

BP: blood pressure

BUN: blood urea nitrogen

Bx: biopsy

CA: calcium

CAD: coronary artery disease

Cap: capsule

CAPD: continuous ambulatory peritoneal dialysis

CBC: complete blood count

CCI: Canadian Classification of Health Interventions

CCKNOW: Crohn's and Colitis Knowledge Score

CCP: Canadian Classification of Diagnostic, Therapeutic and Surgical Procedures

CDA: Clinical Document Architecture

CDHA: Capital District Health Authority

CDM: Chronic Disease Management

CEN: European Committee for Standardization (Comité Européen de Normalisation)

CEN/TC251: European Committee for Standardization Technical Committee Health Informatics

CIHI: Canadian Institute for Health Information

CIRESSS : Centre Informatis, de Recherche Evaluative en Services et Soins de Sant

CHAMP: Clinicians, health informaticians, administrators, medical educators and patients

CHI: Canada Health Infoway

CHOL/HDL ratio: cholesterol/high density cholesterol lipoprotein ratio

CHPSTP: Canadian Institute for Health Research Health Informatics PhD/Postdoc Strategic Training Program

CK: creatinine kinase

CKD: Chronic Kidney Disease

Cl: chloride

CN: central nervous system

CO2: carbon dioxide

CORR: Canadian Organ Replacement Register

Cr: Creatinine

CUI: Concept Unique Identifier for a UMLS concept

CVA: cerebral vascular accident

CVS: cardiovascular system

D/C: discontinue

Diab: diabetic

DM: diabetes mellitus

DMHx: diabetes mellitus history

Dx: diagnosis

EDTA: European Dialysis and Transplant Association

eHealth: electronic health

EHR: Electronic Health Record

EMR: Electronic Medical Record

ENA: extractable nuclear antibodies

ENT: ear, nose and throat

FAQs: frequently asked questions

FeSO4: ferrous sulphate

GGT: gamma glutamyl transferase

Glu: glucose

GP: general practitioner

Hb: hemoglobin

HbA1C: glycosylated hemoglobin

HBV Surface AB: hepatitis B virus surface antibodies

HBV Surface AG: hepatitis B virus surface antigens

HBV/HCV: hepatitis B virus/hepatitis C virus

HCT: hematocrit

HCV AB: hepatitis C virus antibodies

HD: hemodyliasis

HDL: high density liproprotiens

Hemo: hemodyliasis

HGB: hemoglobin

HIMSS: Healthcare Information and Management Systems Society

HIPAA: Health Insurance Portability and Accountability Act

HL7: Health Level 7

HL7 CD: Health Level 7 Concept Descriptor

HL7 CDA: Health Level 7 Clinical Document Architecture

HL7 RIM: Health Level 7 Reference Information Model

HRN: hypertension

ICD: International Classification of Diseases

ICD-9: International Classification of Diseases, Ninth Revision

ICD-9-CM: International Statistical Classification of Diseases, Injuries, and Causes of Death, Ninth Revision, Clinical Modification

ICD-10: International Statistical Classification of Diseases and Related Health Problems, Tenth Revision

ICD-10-CA: International Statistical Classification of Diseases and Related Health Problems, Tenth Revision, Canada

IBD: Inflammatory Bowel Disease

IBDQ: Inflammatory Bowel Disease Questionnaire

IHE: Integrating the Healthcare Enterprise

ICTs: information and communication technologies

Ind bilirubin: indirect bilirubin

INR: coagulant response time

ISO: International Organization for Standardization

ISO/TC215: International Organization for Standardization Technical Committee Health Informatics

K: potassium

Kcal: kilocalorie

L: liter

LD: lactate dehydrogenase

LDL: low density lipoprotiens

LFT: liver function test

LL: left lung

MCH: mean cell hemoglobin

MCHC: mean cell hemoglobin concentration

MCV: mean corpusular volume

Meds: medications

Mg: milograms

Mil/min: milliters per minute

mM/TV: millomolar/tidal volume

mmol/L: millimole per liter

MMTx: MetaMap Transfer

MPV: mean platelet volume

Na: sodium

NCHS: National Center for Health Statistics

O/E: on examination

OD: overdose

OHG: oral hypoglycemic drugs

OID: Object Identifier

PD: progressive disease

PGY1: post graduate student year 1

pH: hydrogen ion concentration

Phos: phosphorus

PLT: platelets

PO: by mouth

PO4: phosphate

Pt: patient

PTT: protothrombin time

PSI: Published Subject Indicator

Qh5: every 5 hours

RBC: red blood count

RDW: red cell distribution count

RT: right

Rx: treatment

Sat%: percentage of saturation

SDO: Standards Development Organization

SF-36: Short Form-36 Questionnaire

SNOMED CT: Systematized Nomenclature of Medicine Clinical Terms

SNOMED RT: Systematized Nomenclature of Medicine Reference Terminology

SPL: Structured Product Labeling

SQL: Structured Query Language

SR: stimulus response

Tab: tablet

TIBC: total iron binding capacity

Tot bilirubin: total bilirubin

Total CO2: carbon dioxide content, also known as bicarbonate

TSH: thyroid stimulating hormone

U/A: urine analysis

UMLS: Unified Medical Language System

WBC: white blood count

WHIC-CDM: Western Canada Chronic Disease Management Infostructure initiative

WHO: World Health Organization

Wk: weeks

XML: eXtended Markup Language

XSL: eXtended Markup Language Style Language

XTM: eXtended Markup Language Topic Maps

Yr: year

@: at

↓: decrease

↑: increase

→: leading to

♂: male

⊘: none, no

#: number

ν: positive

⊕: positive

+: plus

×: times

C̄: with

GLOSSARY

Boundary infostructure: a compound concept formed from boundary objects and a combination of the words information and infrastructure

Boundary object: an intellectual tool that is flexible enough to deal with needs and constraints of several parties while retaining a common identity across sites (Note: term is coined by Star and Griesemer (1))

CHAMP Community of Learners: the context of learning from the perspective of clinicians, health informaticians, administrators, medical educators and patients

Common ground: the knowledge shared by two communicating agents

Discharge summary: a complete story of a medical episode told in a way that encompasses the working behaviour and mental models of the practitioners generating it

eHealth: health care practice which is supported by electronic processes and communication

Health informatics: interdisciplinary study of information and communications systems in health care

Health Level 7 Clinical Document Architecture: a document structuring standard based on the HL7 Reference Information Model

Health Level 7 Reference Information Model: an information model that constrains how information will be represented using XML schema for data types, vocabulary, narrative blocks and structured documents

Informatics: "the discipline of science which investigates the structure and properties (not specific content) of scientific information, as well as the regularities of scientific information activity, its theory, history, methodology and organization" (2)

Information Therapy: Information therapy is the timely prescription and availability of evidence-based health information that is made available to the right person at the right time

Infosphere: "the sphere of human activity concerned with the collection and processing of information, esp. by computer" (2)

Info-poor: information poor

Info-rich: information rich

Infoglut: the problem of information overload

Nosology: science of disease classification

Patient journey: the path followed by a patient through his/her encounter with the clinical system and its interpretation by members of the CHAMP Community of Learners

Pragmatic interoperability: when the intended effect of a communication is the same as its actual effect

Semantic interoperability: systems can use the information that has been exchanged, and users can access similar classes of digital objects consistently and coherently

Social world: the actors trying to solve scientific problems are diverse, answer to a different set of audiences and pursue a different set of tasks because they inhabit different social worlds

SNOMED Clinical Terms: a terminology system that resulted from the merger between SNOMED RT and Clinical Terms from the United Kingdom, a terminology previously known as the READ Codes

Syntactic interoperability: different systems interpret the form of the data the same way and can exchange data

XML: eXtended Markup Language is a key contribution of the Semantic Web community

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Chapter I: Introduction

Pragmatic interoperability problems arise when the intended effect of a communication differs from its actual effect. To avert these problems, an information model is sought which supports semantic interoperability among electronic health resources used for communication and education. This interoperability should exhibit benefits of completeness and seamless integration of information and data.

I.A. Research Statement

The research aim was to model the common ground in the communication space and create a semantic foundation for improving the pragmatic proficiency of authors and the pragmatic competency of learners. The research question was: How might the creation of a boundary infostructure bridge perspectival differences among communities of practice and produce electronic health resources that are more semantically interoperable than those produced by current infostructures?

The research methods were from health informatics, an interdisciplinary field. Health informatics is the study of information and communication systems in healthcare (1). The healthcare context was chronic disease. The solution must be capable of supporting communication among five communities of practice (clinicians, health informaticians, administrators, medical educators and patients) who viewed chronic disease concepts from different perspectives. It must enable semantic interoperability among electronic health (eHealth) resources used for information flow and interpretation by computers in different contexts.

There are three levels of interoperability: syntactic, semantic and pragmatic. Syntactic interoperability existed if different systems interpreted the form of the data the same way and could exchange data. Semantic interoperability existed if systems could use the information that had been exchanged, and users could access similar classes of digital objects consistently and coherently. Pragmatic interoperability problems arose when the intended effect of a communication differed from its actual effect. The objective was to support semantic interoperability among eHealth resources used for communication and reasoning so as to avert pragmatic interoperability problems.

The research was constrained to achieving semantic interoperability among data resources and education resources using standards resources to facilitate interoperability.

Data resources included clinical data warehouse, scanned paper chart, discharge abstracts, dictated discharge summaries, electronic discharge summaries and disease registry entries. These resources were authored by clinicians and administrators.

Education resources included texts in a web portal that were designed to assist patients living with Inflammatory Bowel Disease (IBD) to better manage their health and to help make lifelong learning a reality for patients and their caregivers. Texts originated from patient-to-patient, clinician-to-patient and clinician-to-clinician communication. The patients were given information therapy by an interprofessional team composed of clinicians, health informaticians, medical educators and patient representatives during a study that ran from 2003-2004. Information therapy is the timely prescription and availability of evidence-based health information that is given to the right person at the right time[1].

Standards resources were the specification of the content rules that must be imposed at the document level for structuring; at the terminological level for navigation and aggregation of coded concepts; and at the ontological level for interpretation and reasoning. These resources were authored by health informaticians.

As healthcare workers migrate from using paper to using electronic records, it is imperative to identify and address existing problems that relate to communication and/or interoperability in healthcare. Chronic disease was a particularly suitable choice for this research since chronic care accounts for a significant proportion of healthcare expenditures. Solutions to support chronic disease management offered the greatest benefit to payers and purchasers of health care (2).

[1] http://www.informationtherapy.org/

The interaction between individuals in the same community of practice was made easier because of shared vocabulary and knowledge or common ground (1,3). The framework for the modeling of common ground was the CHAMP Community of Learners (Figure I.1) which drew from the following five communities of practice:

* Clinicians (C) documented clinical care, answered questions posed by patients and performed chronic disease management.
* Health informaticians (H) enabled clinical work through information and communication technologies.
* Administrators (A) implemented data systems, attributed codes to clinical narrative and monitored clinical activity.
* Medical Educators (M) worked at the boundary between theory and practice and used reasoning expressed in clinician documentation to teach future clinicians.
* Patients (P) posed questions to their clinicians and used personal health records as a common point of reference for patient-clinician communication.

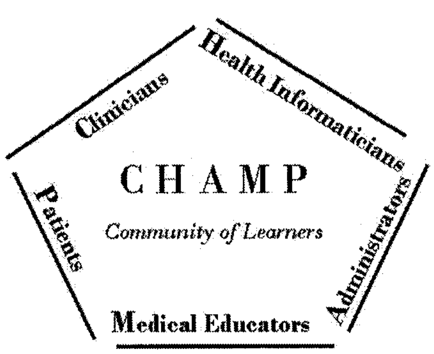

Figure I.1 CHAMP Community Of Learners

The research was subdivided into six hypotheses, which are grouped by problem. The hypotheses associated with the clinical pragmatics problem were:

1. *Data Quality Improvement:* The quality of Discharge Summaries for chronic kidney disease patients can be improved by using a template to prompt medical residents to enter relevant data when documenting care.

2. *Clinical Pragmatics:* The boundary infostructure supports practical data entry, browsing and retrieval for clinical tasks.

3. *Usefulness and Usability:* Patient data provides a repository of activities and results that can be used to generate new medical knowledge for integration with knowledge from external sources and for prompting clinicians at the time of care.

The semantic interoperability hypotheses were:

4. *Constrained Terminology:* Semantic interoperability among electronic health resources can be achieved using a range of UMLS source vocabularies that provide domain coverage.

5. *Commensurability of Different Classifications:* We can make commensurable the different classifications used by members of the CHAMP Community of Learners by grounding the symbols used for encoding clinical events in nosology systems (ICD and SNOMED), thesauri and eHealth resource examples.

6. *Common Ground:* Topic maps can function as the infostructure "glue" to mediate learning at the boundary between and among different communities of practice.

I.B Research Overview

HEALNet investigators recommended that the Canadian research agenda for health informatics be dominated by the requirements for usable, useful and used systems (4). There was a current lack of implementations within Canada of SNOMED Clinical Terms (CT) (5). "The SNOMED CT Core terminology provides a common language that enables a consistent way of capturing, sharing and aggregating health data across specialties and sites of care terminology systems" (5). It would be useful to know to what extent a "common language" recommended for future electronic health records was currently utilized in patient records and patient portals. It would be pragmatic to evaluate whether interventions designed to make clinical documentation more complete and interoperable were usable in practice.

Program directors needed a usable chronic disease management solution that spanned time and space since chronic conditions persisted for a long period of time (6). A potential solution was medical portals designed to provide access "to the physician, the hospital administrator, the resident, nurse, the insurer or the consumer of health services" (7). Such solutions required a trained workforce that provided user support to clinicians and their patients (8-10). The clinical profession should provide information to their patients on which information to trust (11).

The compound concept, *boundary infostructure*, is formed from *boundary objects* and a combination of the words *information* and *infrastructure*. The term *boundary object* was coined by Star and Griesemer to describe intellectual tools. They are:

> *both plastic enough to adapt to local needs and constraints of the several parties employing them, yet robust enough to maintain a common identity across sites. They are weakly structured in common use and become strongly structured in individual site-use. Like a blackboard, a boundary object sits in the middle of a group of actors with divergent viewpoints* (1 *p. 46).*

This research describes the process of creating boundary infostructures for chronic kidney disease and inflammatory bowel disease to provide semantic interoperability among individuals from different communities of practice. The focus for the former was chronic disease management using patient data from medical charts, discharge summaries and hospital information systems. The focus for the latter was a patient portal providing information therapy and virtual clinic functions. Information therapy is the provision of information to help ensure that the patient is an informed participant in his or her healthcare. The virtual clinic supported clinician-patient interaction through electronic means. The chronic disease boundary infostructure was formed from the merger of the two condition-specific infostructures.

For the chronic kidney disease infostructure, the syntactic integration was based on information architecture standards. HL7 Clinical Document Architecture is a document structuring standard based on the HL7 Reference Information Model. The information model constrained how information would be represented using XML schema for data types, vocabulary, narrative blocks and structured documents. The semantic integration was based on controlled vocabularies for diagnoses, vital signs, laboratory results, radiology results, medications and procedures. The semantic interoperability solution was via a network of boundary objects. The information was presented in different contexts depending of the community of practice. The clinician context was a discharge summary, the administrator context was an initial registration form for the Canadian Organ Replacement Register, the medical educator context was a teaching case and the patient context was a personal health record. Clinical documents were generated from the CIRESSS clinical data warehouse for patients from Sherbrooke, Quebec. The results of a query to the CIRESSS system were normalized using HL7 Clinical Document Architecture and terminology systems. The clinical documents from multiple sources were semantically indexed using controlled vocabularies and put into a repository. A topic map was created that linked the concepts and document structures to instances in the repository.

For the inflammatory bowel disease infostructure, the syntactic interoperability was based on the ISO Topic Map information architecture standard and the source code necessary for generating a website from a topic map. The semantic interoperability was based on encoding clinical concepts in narrative to UMLS concept identifiers. The items in the patient portal were semantically indexed and put into a Patient Information Repository. The semantic knowledge permitted inferences to be made and the pragmatic use was to answer pre-constructed questions by compiling information across subject references.

The objective of this thesis was to create a boundary infostructure that accommodated electronic health resources from disparate sources, and to use it as a testbed to demonstrate that resources created using a boundary infostructure would be more semantically interoperable and computer-interpretable than resources currently produced.

The practice of medicine is inherently a process of information handling. The pencil or ballpoint pen serves as a tool to create the handwritten medical record. The clinician does not have to be consciously aware of using it when he/she is documenting patient information. The clinical documents are merged with reports from the hospital information systems, such as laboratory and radiology, to create the patient's paper chart which is then stored in medical records. The different communities of practice—clinicians, health administrators, administrators, medical educators and patients—view the patient chart differently. It serves as a boundary object for coordinating and communicating clinical care. Doctors, nurses, health administrators, insurers, government and disease registries use it to support their information needs (12). It is created by combining information that has been articulated from different viewpoints.

There are ways to make the chart information machine-processable and reusable. Documents are the currency of workflow between humans (13) and physicians are comfortable with a document-centric approach to automation (14). The discharge summary provides a complete story of a medical episode and is told in a way that encompasses the working behaviour and mental models of the practitioners generating it. Making the discharge summary electronic is feasible using eXtended Markup Language (XML) and the HL7 Clinical Document Architecture data schema. Information in the discharge summary could be reused to populate the patient's personal health record, complete a patient registration form for a registry and generate a teaching case. Electronic documents take their meaning from boundary objects. These facilitate the linking of clinical documents of similar orientation by providing semantic interoperability. These boundary objects were drawn from terminology systems and information architecture standards.

The boundary objects provided a way for users to retrieve relevant clinical documents and interpret their contents. The pragmatic proficiency of the authors of the clinical documents should improve as they receive feedback on how their documentation was interpreted for a particular task, e.g., chronic disease management. The pragmatic competence of patients should improve through integration of the clinical documents with subject references in an interactive patient-clinician communication service, such as a patient portal. All learners benefit if use of the boundary infostructure leads to the emergence of a "mutual semantic foundation for cooperative work" (15).

The subject references were an attempt to unambiguously identify the subject of a topic to a human being. The Oxford English Dictionary aimed for entries that were clear and unambiguous and used helpful examples to clarify where appropriate. A similar approach is envisioned in the boundary infostructure. Artefacts, such as the subject references, reified practice and were boundary objects.

There were no entries in the New Edition of the Oxford English Dictionary (16) for either the term *boundary object* or the term *infostructure*. Four entries, *informatics, infosphere, info-poor* and *info-rich*, are useful for this discussion. *Informatics* is "the discipline of science which investigates the structure and properties (not specific content) of scientific information, as well as the regularities of scientific information activity, its theory, history, methodology and organization". *Infosphere* is "the sphere of human activity concerned with the collection and processing of information, esp. by computer". *Info-poor* and *info-rich* are the combining forms for information-poor and information-rich (16). Another compound term, *infoglut*, is useful for describing the problem of information overload.

The term *boundary infrastructure* was used by Bowker and Star in their book, *Sorting Things Out: Classifications and Their Consequences.* Concepts are categorized by classification systems. Every successful standard imposed a classification system for organizing actions or things, whereas the classifications that do not become standards may continue to be used locally (12). These local classifications are tied to identity and practice patterns and should be attended to in infostructure design. Every classification system is a boundary object because it serves as a common point of reference for managing knowledge across a given boundary. Nosology is the science of disease classification, and the different nosology systems classify diseases using different facets. Each user has a variable understanding of the terminology and of its categorization in a nosology system. The set of perceptions of the multiple communities of practice are needed to get a complete picture of an information object, such as a clinical document.

> *What we gain with concept of boundary infrastructure over the more traditional unitary vision of infrastructures is the explicit recognition of the differing constitution of information objects within the diverse communities of practice which share a given infrastructure* ((12),, *Chapter 9).*

The Canadian Advisory Committee on Health Infostructure identified five interrelated components needed to support eHealth activities: organizations and people, process, information, technology and standards (17). Their gap analysis stated:

> *Until the use of electronic information and technology is part of the culture of health care professionals, especially for physicians and nurses, their benefits will never be fully realized. Initiatives should concentrate on encouraging health care professionals to use and benefit from electronic information and technology whilst integrating it with everyday practice?* (18)

I.B.1 Principles

The principles that guided this research and the writings that influenced them include:

* teach clinical concepts by means of examples and by practice (19);
* harmonize standards that influence semantic interoperability (20);
* be pragmatic and seek a solution that is useful, usable and used (4);
* seek an optimum balance between usefulness and usability of data (21);
* leverage Semantic Web knowledge in crafting the boundary infostructure (22);
* mediate classification differences through links to training materials that offer an explanation (12); and
* conceive of classifications and standards as key to a community of practice's knowledge strategy (23).

I.B.2 Research Sites

Three sites were involved with this research.

1. Renal Program, Province of Nova Scotia and Division of Nephrology, Department of Medicine, Capital District Health Authority and Dalhousie University, Halifax, Nova Scotia, Canada
2. Inflammatory Bowel Disease Clinic, Division of Gastroenterology, Department of Medicine, Capital District Health Authority and Dalhousie University, Halifax, Nova Scotia, Canada
3. Centre Informatis, de Recherche Evaluative en Services et Soins de Sant, (CIRESSS) and Centre for Research and Evaluation in Diagnostics, Université de Sherbrooke, Quebec, Canada.

I.B.3 Research Methods

I.B.3.1 Overview

The first hypothesis was that the quality of discharge summaries for chronic kidney disease patients could be improved by using a template to prompt medical residents to enter relevant data when documenting care. The method was to construct two boundary objects, the Chronic Kidney Disease Discharge Summary template and the Clinical Document Repository, and evaluate whether use of the template led to discharge summaries that were more complete, interpretable and semantically interoperable. The template featured a clinical calculator, information lookup (primary renal diagnosis, co-morbidity diagnosis and lab tests) and medication query using the Nova Scotia Formulary. The participants were randomized to start with transcription followed by template or template followed by transcription. The information source was the paper chart of a real patient for a particular hospital stay. Clinicians created a coded electronic discharge summary compliant with the HL7 Clinical Document Architecture (CDA) Release 2.0 specification and a dictated discharge summary for transcription by secretarial resources. Data interpretation was supported by links to SNOMED CT concept descriptions and Canadian Institute for Health Information (CIHI) discharge abstract. The discharge summaries were scored for their pragmatic qualities and participants were asked for feedback on their experience. Electronic discharge summaries and the chart entries they referenced were stored as CDA examples in the Clinical Document Repository. The information was then rendered in different forms depending on user context in the CHAMP model.

The second hypothesis was that the boundary infostructure supports practical data entry, browsing and retrieval for clinical tasks. A pragmatic approach was used to evaluate the attributes of the boundary objects. The boundary objects needed to support Grice's Cooperative Principle for pragmatic communication (24). They needed to enable linking of clinical documents of similar orientation and support the semantic indexing of patient cases with links to subject references.

The third hypothesis was that patient data provided a repository of activities and results that could be used to generate new medical knowledge for integration with knowledge from external sources and for prompting clinicians at the time of care. One criterion was to determine if the infostructure could deliver "the right information, to the right person, at the right time, in the right form, in the right place, and for the right price" ((25) p. 141). The testbed framework was constructed from boundary objects (template for HL7 Clinical Document Architecture, SNOMED nosology system, ICD nosology system, UMLS and topic maps metadata). The discharge summary content was transformed into other forms, including personal health record, patient registration for disease registry, discharge abstract and teaching case (26) based on the Western Health Information Collaborative Chronic Disease

Management data standard (5). The clinical pragmatics (27) of clinicians entering data into a discharge summary was evaluated for its practicality.

The fourth hypothesis was that semantic interoperability among electronic health records could be achieved using a range of UMLS source vocabularies that provided domain coverage. Terminological extraction methods were used to identify concepts that could be encoded from text corpora gathered from the clinical domains. These were augmented with the controlled vocabulary terms, in French and English, from the CIRESSS data dictionary entries.

The fifth hypothesis was that we could make commensurable the different classifications used by members of the CHAMP Community of Learners by grounding the symbols used for encoding clinical events in nosology systems (ICD and SNOMED), thesauri and electronic health resource examples. Topic maps were used to produce a dual view of the information space. The resource-centric view described the examples in the Clinical Document Repository and Patient Information Repository with reference to topics. The subject-centric view provided the references to information about topics. The subject reference becomes a symbolic surrogate (28) and should facilitate shared understanding that is human-readable and computer-processable. Knowledge and understanding imply a human host. This research investigated what could be provided to human users by a boundary infostructure.

The sixth hypothesis was that topic maps can function as the infostructure "glue" to mediate learning at the boundary between and among different communities of practice. The three-layer topic map was composed of subjects, structure and context (Figure I.2). The subjects were the organizing principle for concepts chosen for completeness analysis. The concepts were the controlled vocabulary that could be represented with a unique concept identifier in UMLS Version 2006AA with mappings to SNOMED (versions CT and 3.5) and ICD (versions 9, 9-CM and 10-CA). The structure was the information architecture and its expression in semantic classes, nosology systems, lexicons and health information standards. The relationship between subjects and structure supported semantic indexing of the examples in the repositories. The context was the use of subjects and structures in normal practice by members of the CHAMP Community of Learners.

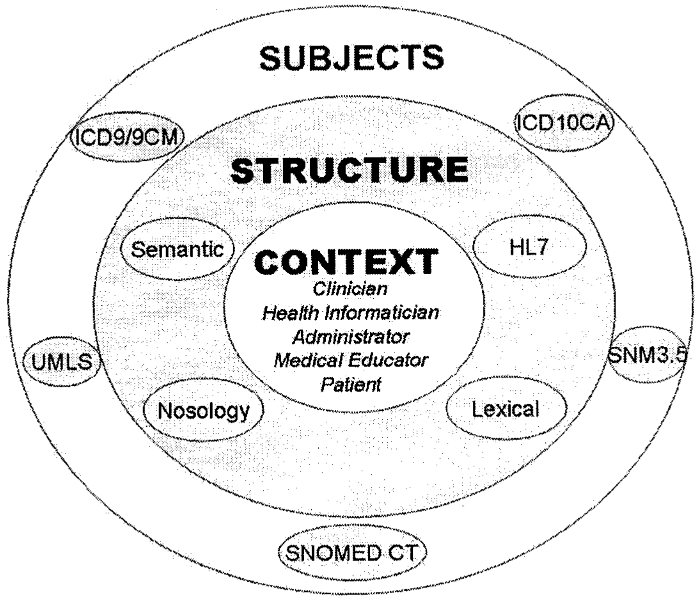

Figure I.2 Three-Layer Topic Map Of Subjects, Structure, Context

The Clinical Document Repository was composed of entries from a patient chart, discharge summaries, teaching cases and hospital data transformed into a common structure using HL7 Clinical Document Architecture. The Patient Information Repository was composed of webpages from the HealthInfoRx™ patient portal. The Chronic Kidney Disease and Inflammatory Bowel Disease topic maps merged the three-layer model with the repository examples.

The patient portal was checked for its ability to deliver the right information. This was done by determining whether the current site supports navigation from a question in a knowledge quiz to content that answers the question. The questions that failed the evaluation were then posed to the Inflammatory Bowel Disease topic map integrated with the patient portal. This new approach should improve pragmatic competency of learners. The Socratic Completeness method was used for this evaluation. This method used semantic connections between concepts to focus its search for useful information (29). The semantics accurately reflected the potential reasoning ability if the correct conclusion could be found based on the right series of questions (29).

I.B.3.2 Materials

The contributions to the text corpus were authored by members of the CHAMP Community of Learners.

1. Clinicians: patient chart entries; dictated and transcribed discharge summaries; electronic discharge summaries; and answers to Frequently Asked Questions.
2. Health Informaticians: HL7 Clinical Document Architecture specification (30); HL7 Template for Chronic Kidney Disease Discharge Summary; HL7 Template for PatientRx in HealthInfoRx™ virtual clinic; Western Health Information Collaborative Chronic Disease Management data standard (5); CIRESSS clinical data warehouse data dictionary; and IBD Factors metadata for patient portal for Inflammatory Bowel Disease patients.
3. Administrators: Chronic Kidney Disease Diagnosis list; Canadian Organ Replacement Register Patient Registration Form; and Canadian Institute for Health Information Discharge Abstract Database records.
4. Medical Educators: teaching cases for undergraduate and continuing medical education; patient curriculum; pamphlets; Crohn's and Colitis Knowledge test; and glossary for patient education.
5. Patients: questions posed to clinicians; discussion forums; and Cochrane plain language summaries for Inflammatory Bowel Disease Systematic Reviews.

The electronic health resources produced in three studies were the inputs to this research.

1. Transcription Versus Electronic Health Record Templates for Chronic Kidney Disease Discharge Summary. The electronic discharge summaries were produced by clinicians using direct data entry via an HL7 Template and by clinicians using a dictation and transcription system. The study was conducted in 2006.
2. Utilisation de topic maps et HL7 dans CIRESSS. The electronic discharge records of anonymized patients were generated from queries posed by health informaticians to a clinical data warehouse containing hospital data. The study was conducted in 2006.
3. HealthInfoRx™: Lifelong Learning for Chronic Disease Patients and Their Caregivers. The electronic webpages were produced by clinicians, health informaticians, medical

educators and patients. Study investigators recruited 76 patients from the Inflammatory Bowel Disease Clinic, Nova Scotia. Patients showed moderate improvement in knowledge test scores, but responded "don't know" to question items more often than expected. The study was conducted from February 2002-March 2004 (31,32).

I.B.3.3 Study: Transcription Versus Electronic Health Record Templates For Chronic Kidney Disease Discharge Summary

The focus of this study was the pragmatic proficiency of clinicians, who were the authors of the discharge summary. A standard paper chart served as the information source for residents who generated two versions of a discharge summary: 1) dictated and transcribed, and 2) electronic discharge summary stored as an HL7 Clinical Document Architecture in XML. Over 70% of the chart pages contained handwritten information, so generation of an electronic discharge summary without human intervention was not an option. The intervention was a template that coded the content concurrent with data entry and linked the content to concept descriptions.

This study was used to test hypotheses 1, 2 and 3 described in section I.A above. Clinical pragmatics issues, including practical data entry and the behaviour of clinical terminology in software, were investigated. The discharge summaries produced from this study were analyzed for subject coverage. The process produced the Chronic Kidney Disease Topic Map Version 1.

I.B.3.4 Study: Utilization De Topic Maps Et HL7 Dans CIRESSS

The focus of this study was improving the pragmatic competency of learners. The research investigated semantic interoperability among patient cases from bilingual sources (English and French), and case indexing for retrievals that could be used to learn about the different ways information is categorized. A query for patients with chronic kidney disease, diabetes and hypertension was submitted to CIRESSS clinical data warehouse maintained by researchers at the Centre de Recherché Clinique, Centre Hospitalier Universitaire de Sherbrooke. The result set was 160 patient cases for a total of 302 hospital visits. The data consisted of diagnoses, procedures and service information, similar to the information captured for the Canadian Institute for Health Information's Discharge Abstract Database. Five patient cases for a total of 17 hospital visits had additional information on lab and radiology results.

This study was used to test hypotheses 3 and 6, described in section I.A above. All cases were transformed into HL7 Clinical Document Architecture XML files and merged with those from the first study (I.B.3.4.1). All cases were semantically indexed using subject and structure topics in Chronic Kidney Disease Topic Map Version 1. Additional topics were added to reflect differences in code systems used between the two jurisdictions, Halifax and Sherbrooke. New boundary objects were created for semantic indexing of patient cases. The process led to the development of the Chronic Kidney Disease Topic Map Version 2.

I.B.3.5 Study: HealthInfoRx™ : Lifelong Learning For Chronic Disease Patients And Their Caregivers

The focus of this study was improving the pragmatic proficiency of authors and the pragmatic competency of learners. The objective was to learn about the links between questions in the knowledge quiz given to patients in the HealthInfoRx™ study and contents in the patient portal. It used a Socratic Completeness analysis of HealthInfoRx™ pre and post integration with the Inflammatory Bowel Disease topic map for referencing site contents. The HealthInfoRx™ patient portal was developed as a partnership between investigators in Medical Informatics and Gastroenterology, and a commercial partner (Simuplex) for curriculum development. The content consisted of Frequently Asked Questions (N=93), glossary (N=398), patient education modules (N=13), pamphlets (N=5), Cochrane plain language summaries (N=10), discussion forum (N=1) and continuing medical education module (N=1). Patients' learning outcomes were assessed with a 24-item Crohn's and Colitis Knowledge test given pre and post (N=47). An analysis of "don't know" responses revealed room for improvement in site organization. Manual and automatic terminological extraction methods were used to identify clinical concepts in text.

This study tests hypotheses 4, 5 and 6, described above in section I.A. The process led to the development of the Inflammatory Bowel Disease Topic Map Version 1.

I.B.4 Research Learning Experiences

This research was informed by participation in the first cohort of the Canadian Institute for Health Research Health Informatics PhD/Postdoc Strategic Training Program (CHPSTP) from January 2003 to December 2004. Participation included a role as the student representative on the Program Advisory Committee.

I.B.4.1 RLE02 Frontiers Of HI Research

Dr. Francis Lau, principal investigator, CHPSTP, led RLE02. Trainees were required to write a paper for submission to a journal or conference and complete a project. My paper, *Evaluating HL7 Using Medical Education Curriculum Content*, was unsuccessfully submitted to MedInfo2004. I partnered with trainee Dr. Francis Ho, a family physician, for our project, *Comparison of HL7 Message and Document Specifications for Diabetes Care*. This project gave me the opportunity to utilize the HL7 Message Development Framework tools and Clinical Document Architecture specification. Our objective was to develop a Diabetes Information Model based on HL7 and to discuss the pros and cons of two HL7 Version 3 specification frameworks (message-based and document-based). This work furthered my understanding of HL7 Version 3. I chose to continue my research using the document-based approach. However, the Western Health Information Collaborative Chronic Disease Management specification (also known as the Canadian Chronic Disease Management specification in the May 2006 HL7 Ballot) was message-based (5). That specification was utilized in this research.

I.B.4.2 RLE03 Knowledge Management And Transfer

My supervisor, Dr. Michael Shepherd, and my mentor, Dr. Andrew Grant, were co-leads of RLE03. The proposal, *Utilisation de Topic maps et HL7 dans CIRESSS*, was jointly submitted with CHPSTP Trainee, Andriy Moshyk. The goal of the project was to elaborate the methods of representation of medical data in CIRESSS using HL7 and semantic indexing of prototypical cases using topic maps.

I.B.4.3 Co-Investigator HealthInfoRx™

For the inflammatory bowel disease domain, the research team of health informaticians (David Zitner, Grace Paterson, John Ginn) and clinicians (Desmond Leddin, Donald MacIntosh, Jennifer Stewart) was successful in attracting $437,000 in funding from the Office of Learning Technologies and in-kind support for study, *HealthInfoRx™: Lifelong learning for chronic disease patients and their caregivers*. I actively participated in the design phase of the research in 2002, but played a minor role during the implementation phase. In the present Canadian healthcare system, there was limited adoption by the payers of solutions that help patients self-manage their condition. Consequently, the project was suspended at the end of 2004. In this research, I aimed to improve the site's ability to answer questions posed by patients and by the Crohn's and Colitis Knowledge instrument (32).

I.C Roadmap

The literature review is presented in Chapter II. Topics include boundary infostructures; boundary objects; communities of practice; health infostructures; medical informatics competency in medical education; nosology, nomenclature and classification systems; ontology creation; and pragmatic proficiency and competency.

The overview of topic maps is presented in Chapter III. Study one, Transcription versus Templates for Discharge Summaries, is presented in Chapter IV. Study two, Clinical Data Warehouse Discharge Records, is presented in Chapter V. Study three, Patient Portal Webpages, is presented in Chapter VI. The evaluation for CHAMP Community of Learners is presented in Chapter VII and for Topic Maps is presented in Chapter VIII. The conclusions and topics for further research are described in Chapter IX.

Chapter II: Literature Review

The plan of the literature review is as follows. The concepts of boundary infostructures and boundary objects are introduced. The review of boundary objects introduces us to the concept of communities of practice, and the role they play in learning. The current thinking on infostructures and medical informatics competencies in medical education provides a viewpoint and a rationale for this work. The structuring of knowledge in existing nosology, nomenclature and classification systems is described. The central issue of heterogeneity in biomedical ontology is introduced, which provides a rationale for structuring the information space as a topic map so that different views of a concept can be made visible. The dual objectives of improving the pragmatic proficiency of authors and the pragmatic competency of learners are explored in the literature.

At the end of this chapter, the conclusions reached in the literature review are mapped to the six hypotheses. These are:

1. Data Quality Improvement: The quality of Discharge Summaries for chronic kidney disease patients can be improved by using a template to prompt medical residents to enter relevant data when documenting care.
2. Clinical Pragmatics: The boundary infostructure supports practical data entry, browsing and retrieval for clinical tasks.
3. Usefulness and Usability: Patient data provides a repository of activities and results that can be used to generate new medical knowledge for integration with knowledge from external sources and for prompting clinicians at the time of care.
4. Constrained Terminology: Semantic interoperability among electronic health resources can be achieved using a range of UMLS source vocabularies that provide domain coverage.
5. Commensurability of Different Classifications: We can make commensurable the different classifications used by members of the CHAMP Community of Learners by

grounding the symbols used for encoding clinical events in nosology systems (ICD and SNOMED), thesauri and eHealth resource examples.

6. Common Ground: Topic maps can function as the infostructure "glue" to mediate learning at the boundary between and among different communities of practice.

II.A Boundary Infostructures

The idea of deliberately constructing a *boundary infostructure* so that it explicitly recognizes "the differing constitution of information objects within the diverse communities of practice that share a given infrastructure" came from Bowker and Star (12).

The analysis of boundary objects has been used as a method for evaluating ways that users meet infrastructure in digital libraries (33), museums (34), categorization work (35) and product development (36). While a boundary infostructure may emerge from shared use of boundary objects (12,36), the literature says little about deliberate construction of a boundary infostructure. At this time, it appears that the approach taken in this research is novel.

II.B Boundary Objects

The concept of object is that of tools, techniques, artifacts and stories that are used "in the service of an action and mediate it in some way" ((12), page 298). The concept of a boundary object describes objects that are sharable across different problem-solving contexts. It enables consideration of divergent viewpoints. The boundary object plays an important role in solving the semantic interoperability problem (33).

Star and Griesemer (34)based their notion of boundary objects on intellectual tools which play the roles of containers and carriers because they help carry meaning. They identified four types of boundary objects.

1. *Repositories: "objects which are indexed in a standardized fashion" (e.g., eHealth resources)* ((34), page 410)
2. *Ideal type: "differences in degree of abstraction" (e.g., models)* ((34), page 410)
3. *Coincident boundaries: "same boundary but different internal contents" (e.g., websites and communication portals)* ((34), page 410)

4. *Standardized forms: "methods of common communication" (e.g., document templates)* ((34), page 411)

The following subsections explore the literature surrounding each of these four types of boundary objects.

II.B.1 Repositories Of eHealth Resources

The World Health Organization defines eHealth as "the cost-effective and secure use of information and communications technologies in support of health and health-related fields, including health-care services, health surveillance, health literature, and health education, knowledge and research" (37). According to Health Canada's eHealth *InfoSource cybersanté*, eHealth is "an overarching term used to day to describe the application of information and communication technologies in the health sector" (38). The Electronic Health Record is fundamental to eHealth for "sharing of necessary information between care providers"; other uses are found in the "area of continuous medical education and public health awareness and education" (38).

The medical record, in either electronic or paper form, is a boundary object (39). It is part of the organization's infostructure and provides a conceptual framework for analyzing how individuals work together, share information and categorize concepts. The term *medical record* is used for both the physical folder (13)and the body of information it contains. It is traditionally compiled and stored by health care providers. The term *computer-based patient record* implies an integrated record containing entries from all healthcare providers linked to a person identifier. This vision was never realized due in part to the existing electronic data sources that were not interoperable (40). The term *electronic health record* is applied to records that are interoperable among health care providers, and interoperability is a focus of this work.

In 1966, Octo Barnett prepared a report to the National Institutes of Health Division of Research Grants Computer Research Study Section and this report was recently published (13). He described the practice of medicine as "a process of information handling and a natural challenge for today's computer technology". Forty years later, many of the same paper-based practices in hospitals are still being used for information handling. He described how the clinical activities involved a large number of individuals. The information flows from many different sources, "such as the record of vital signs, the nursing notes, and a variety of laboratory tests as well as from repeated physical examinations and interviews with the patient" (13). The medical records are a collection of all the communications and reports that describe clinician work and patient outcomes. Barnett envisioned information processing and rapidity of communication as playing a major role in determining the quality of medical care. However, his vision has not been realized forty years later (41).

One factor that led to the lack of practical clinical information systems is the National Institute of Health's funding policy (41). It was destructive of research projects that were implemented because the funding stopped at the end of the initial grant period and there was no funding mechanism to ensure sustainability of practice-based implementation of research-based clinical information systems. The result of such funding policies is a lack of advanced electronic health record systems and vendor offerings of outdated and outmoded products (41).

The Canadian experience is much the same. A call for proposals to study the barriers to the adoption, implementation and sustainability of information and communication technologies in the health system specifically excluded any study that wished to evaluate barriers to use of an implemented system (42). To build an evidence base for eHealth, studies need to measure what is changed due to the implementation of electronic health record systems.

The scope of eHealth research is using, processing, sharing and controlling information (43). The values that are considered important to stakeholders are measuring improvement in health. Since this is a confounded by other factors, such as behaviour, the research agenda should focus on systems that are useful, usable and used (4). Longer-term research questions could be aimed at modeling costs and benefits (in terms of health) (43).

Numerous studies have investigated barriers to the use of electronic health records in the clinician community (10,40,44). Researchers found that quality improvement depends heavily on physicians' use of the electronic health record, rather than paper, for clinical tasks (10). The clinical pragmatics problem of practical data entry, presentation and retrieval has to be addressed in the health infostructure (27).

Recent US data suggests that less than 18% of physicians use electronic health records in their offices while 29% of physicians use them in outpatient departments (45). Canadian data indicates lower rates of utilization, with slightly more than 12% reporting in the affirmative to the statement "I am currently using an EMR system for more than just billing and patient scheduling" (44), where EMR stands for electronic medical record. The efforts required to harvest the benefits of electronic health records have to be balanced for each party involved (46). Physicians who use a lead pencil are paid the same rate as doctors who implement sophisticated electronic patient record systems and their pay is inadequate to support the modern health infostructure routinely used by banks and other service industries (47). Any savings from improved care efficiency typically flow to the insurer rather than the provider.

The low diffusion rate indicates a need to influence physicians' social networks. Physicians are more likely to influence the practice patterns of their colleagues than external forces. Physicians have a tight-knit social network and rely on their professional peers as their primary source of information (45). One strategy is to train the present and future medical workforce in the use of electronic health records (45). Another significant barrier to adoption has been vendor volatility. This could be addressed through a common data standard so that the initial investment of creating the electronic health record is not lost (45).

Two systematic reviews evaluated the published research on the impact of record systems on clinician work. The relationship between practice and the recording of practice showed that more research into the role of computerisation is needed. Computerisation has an effect on information flow and the adaptation of nursing work practice to fit the constraints imposed by the computer system (48). There is an impact of electronic health records on time efficiency of nurses and physicians. Poissant et al. studied the time spent documenting clinical care by nurses and physicians (49). Overall, the use of bedside terminals and central station desktops saved an average of 23.5% and 24.5%, respectively, of nurses' documentation time. Conversely, physicians' use of central station desktops for computerized provider order entry was inefficient. Three studies reported increases in work time that ranged from 98.1% to 328.6% per working shift. One reason why nurses are more likely than physicians to gain time efficiencies by using a computer system is their use of standardized forms or templates in documentation (49).

Members of the Healthcare Information and Management Systems Society (HIMSS) take a pragmatic approach to building the infostructure of the electronic health record. Each year they publish guidelines for participation in the interoperability showcase known as IHE (Integrating the Healthcare Enterprise). IHE began in 1998 as a collaborative effort to improve the way healthcare computer systems share information. IHE Canada was formed in 2004 (50).

The attributes of the Electronic Health Record that HIMSS members consider mandatory are illustrative of US influences. Examples include support for HIPAA (Health Insurance Portability and Accountability Act of 1996) and use of the data captured in the electronic health record for the organization's quality and safety program (51). The HIMSS Electronic Health Record definition, attributes and essential requirements lack any reference to improving physicians' lives or patient outcomes. It specifically addresses the interests of insurers and Medicare's pay for performance initiative through certification of electronic health record products (51). It is a boundary object that will require the reconciliation of technical and social issues (52).

> *The Electronic Health Record (EHR) is a secure, real-time, point-of-care, patient-centric information resource for clinicians. The EHR aids clinicians' decision-making by providing access to patient health record information where and when they need it and by incorporating evidence-based decision support. The EHR automates and streamlines the clinician's workflow, closing loops in communication and response that result in delays or gaps in care. The EHR also supports the collection of data for uses other than direct clinical care, such as billing, quality management, outcomes reporting, resource planning, and public health disease surveillance and reporting* (51).

The clinical usability of eHealth resources affects patient care. The clinician uses a conceptual framework akin to telling the story of the patient in relation to the delivery of health care. Many electronic health record systems do not support the story metaphor (53). The failure to appreciate the medical record as a tool that structures the communication among healthcare personnel may help explain the "current paucity of fully integrated, clinically useful electronic records systems" (39).

From this literature review, we learn about ways to shape the Clinical Document Repository and Patient Information Repository as boundary objects. Thus far, the electronic health record is not a successful boundary object because of barriers to use. These barriers include: effects on work practice (48,53); impact on productivity gain (49,54); diffusion amongst ones peers (45); the savings not accruing to the provider (45,47); loss of investment due to vendor volatility (45); poor adoption of interoperability standards (41,51); and the focus on electronic health records as a tool for performance management (51).

Conclusion 1: Use standardized forms or templates to improve productivity of users and clarity of electronic health records.

Conclusion 2: Educate physicians via their social networks to have a positive impact on clinician adoption of electronic health records.

Conclusion 3: Use a common data standard to lessen impact of vendor volatility.

Conclusion 4: Recognize the multifaceted needs of users from different communities of practice.

Conclusion 5: Focus on systems that are useful, usable and used to improve the lives of physicians and their patients.

Conclusion 6: Maintain clinical narrative as this helps establish context.

II.B.2 Models

Models are an abstraction and do not accurately describe the details of any one thing. They are an *ideal type* of boundary object. "Ideal types arise with differences in degrees of abstraction" and are adaptable ((34), page 410). They are abstracted from all perspectives, and may be fairly vague. Information is only elaborated to the extent where it is useful.

For organizational decision processes, the discharge summary report serves the boundary object function of facilitating communication among clinicians and administrators, allowing for local adaptation, but providing for some commonality. Discharge summary reports are an example of an *ideal type* of boundary object (55). In their ideal form, they are "concise, to the point and directive"; they "describe the essence of the case"; they "synthesize data and only give pertinent information"; and they "provide a synthesis of the actions to be taken following the release of the patient from the hospital" (56).Efforts to model the common ground between a system and human users can provide insights into communication difficulties (1).

This research requires a method to explicitly reference what the information is about in the boundary infostructure. The formalization of a conceptualization is called an ontology, and it specifies how a set of concepts relate to each other (28). If topic maps are built from a sound ontology, they can provide semantic interoperability among those applications that use them (28). The notion of published subjects is used in topic maps. This is to emphasize that when information is made Web-addressable it is similar to the act of publishing and should be afforded the same stability that is associated with publication (28).

The terminology systems are a source of published subjects and the discharge summaries are objects that require subject indexing to aid in their interpretation. The goal of the topic maps paradigm is to discover information from others, talking about the same subject, using different terms for the same subject (57). The topic map model handles heterogeneous vocabularies.

Persistence can be used as a surrogate for stability. Terminology systems, such as SNOMED and UMLS, follow the principle that concept identifiers are persistent over time and are never reused (58). A discharge summary expressed using the HL7 Clinical Document Architecture specification is persistent and continues to exist in an unaltered state for a time period defined by regulatory requirements for medical records (30).

The subject-object relation is key to the process of interpretation and the understanding of the sign-situation (59). In order to share knowledge, people need a common channel over which to communicate and a common view of the domain of knowledge. Early in the 20th century, Ogden and Richards wrote a seminal text on the influence of language on thought. Their Semiotic Triangle (Figure II.1) depicts the relationship between thoughts (reference), words (symbols) and things (referent) ((59), p. 11).

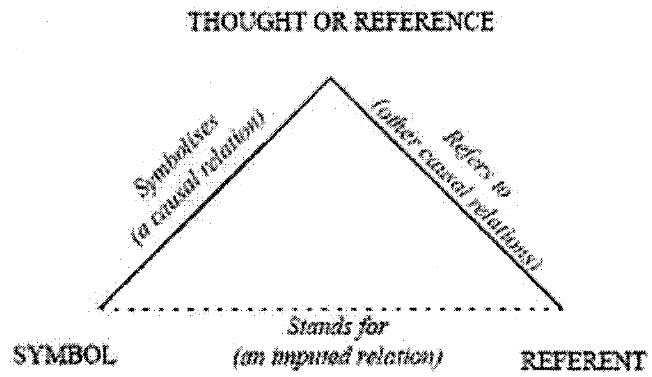

Figure II.1 Ogden And Richards Semiotic Triangle

Difficulties arise when language is treated as though it were a complete system of perfect symbols (59). It is futile to attempt to develop a precisely defined ontology of everything.

There is a pragmatic meaning in language utterances and these utterances interact with the real world to cause a response, such as an ordered action to be physically performed. In medicine, the science for the study of signs of diseases is called semiology. Peirce defined "*Semiosis*" as an action or influence which involves a cooperation of three elements, a sign, its object and its interpretant (59). The HL7 Reference Information Model was influenced by the foundation work on action and meaning by pragmatic philosophers Peirce and James (60).

The five desirable characteristics for reference ontologies are "good lexical coverage, good coverage in terms of relations, compatibility with standards, modularity and the ability to represent variation in reality" (61). Terms and relationships are essential components of interoperability among eHealth resources (62). Categories are types of relations that open the door to semantic indexing, which is indexing with a variety of semantic relations (28).

There are two obstacles to achieving a medical sublanguage for a common understanding of electronically communicated information: the model construction problem and the symbol grounding problem (1). The major prerequisite for a mutual semantic foundation (15) is explicitly expressed concepts understandable by humans and computers. This includes the comparison of different representations to determine whether or not they mean the same thing.

From a pragmatic perspective, the attributes of a communication should conform to commonly agreed-upon standards (24). It is argued that ontology based on the classification of entities in reality rather than the classification of concepts in thought will make a vital contribution to ensuring interoperability of coding systems (63).

Terminological systems play a role in creating a healthcare language to describe all the necessary concepts that might be found in a patient record (1). A standard data structure for a healthcare language forms a knowledge base that encodes semantic relationships between concepts (64-67). Standardized terminological services enable semantic interoperability by functioning as a *middleware* component in infostructures (68). However, end users may be disappointed by the fact that the vocabulary they use is missing or they may disagree with the concept knowledge provided by the server (68).

The tree browser in the UMLS's Rich Release Format Browser displays terms and concepts in a hierarchical format and acquaints the user with data structures in source vocabularies (e.g., SNOMED CT and International, ICD-9-CM, ICD-10, HL7) (69). Another source vocabulary that can be viewed using the tree browser is AI/RHEUM. This is the controlled vocabulary for a clinical decision support system that was designed to support diagnostic reasoning for a class of chronic disease, rheumatic disease (70). It classified patient data into a hierarchical tree. It was successfully used for education of trainees and for triage of data for primary care and emergency care (70). It provides an example of data that is pertinent for data collection, and the data elements are grouped similarly to sections in an HL7 CDA document.

The mapping from terms in the UMLS ontology to a standardized medical record based on the HL7 Reference Information Model maintains the separation of concept knowledge from content as advocated by the European standard, 13606, for electronic healthcare record communication (71).

Criteria used to evaluate which terminology system is appropriate for a need include coding coverage, size, integration and language coverage (72). SNOMED was chosen as the most appropriate coding system for clinical trials (72). The completeness of the mapping of concepts in patient records to SNOMED is a criterion for usefulness. At this time, there is no "gold standard" for completeness (72). SNOMED's compositional approach to clinical coding increases completeness at the expense of clarity, whereas UMLS has clarity at the expense of completeness for clinical encoding (73).

There are published desiderata for controlled medical vocabularies (74,75), clinical terminology servers (76) interface terminologies (77,78) and reference ontology (61). Each approach rests on different criteria.

Every classification system is a boundary object (12). Categorization is a human trait, but no two people categorize things in an identical way. However, the meaning systems of individuals in a community are largely congruent (3). A broad classification system contains categories that are common to multiple user contexts. There is a tradeoff between precision and vagueness in terms of pragmatics.

The relationship between the subjects and the topics is the core of the Topic Map theory. The main theoretical design is one topic for one subject, so if two topics describe the same subject they have to be treated as one unit in the given context (57). The common subjects in two drug information sources were identified through a topic map representation (79), and this method holds promise for identifying common subjects among eHealth resources used for chronic disease.

From this literature review, we learn about desirable characteristics of reference ontology (61); the ability of topic maps to provide semantic interoperability based on ontology (28); and pragmatic constructions with respect to granularity (80) through use of the Peircean approach to subject indexing (28).

Conclusion 7: The classifications should be pragmatic constructions that are vague enough to be common.

Conclusion 8: The UMLS contains a hierarchical classification of patient data for mapping from patient data to medical knowledge in a chronic disease knowledge base, AI/RHEUM, that could serve as an example of a tree representation of document sections and entries.

Conclusion 9: The subject references can elaborate the contents of the Patient Information Repository and the Clinical Document Repository, leading to improvements in pragmatic competency.

II.B.3 Websites And Communication Portals

The Internet provides a common user interface in the form of a web browser. The interface can be made interactive through use of a three-tier architecture that provides flexibility and security and multiple perspectives (7). The repurposing of content to serve different information needs is made possible from a common set of resources. Administrators usually desire information that is aggregated, whereas clinicians desire patient-specific information. Medical portals use appropriate channels to provide information in accordance with user profiles (7).

Berg and Goorman investigated medical information from a sociological perspective. Their "law of medical information" states that "the further information has to be able to circulate (i.e., the more diverse contexts it has to be usable in), the more work is required to disentangle the information from the context of its production" (81). HL7 data standards, such as the Canadian Chronic Disease Management model (5), are designed for a specific context of use. Adapting them in order to find the common ground for chronic disease care (82) and medical education requires further work.

Patient-provider websites support communication among patients and their caregivers through communication portal functions, such as chat function, email function and text messaging. The problem of "infoglut" can be alleviated by providing information therapy to patients using information resources from trusted sources (31). Information therapy is a prescription for health information. Studies have shown that effective support for patient self management required a focus on knowledge deficit and provision of health information resources from trusted sources (82,83).

The HealthInfoRx^{TM} portal (32) supports lifelong learning among the CHAMP Community of Learners. Patients participate by asking questions and sharing their experience of the disease. Clinicians and medical educators participate by answering questions and creating learning resources. Health informaticians participate by providing a secure medium for patient-provider and patient-patient communication, and by organizing site content (32). Administrators can use the feedback from patients to build a better healthcare system.

The provision of a patient internet portal may widen the digital divide between the info-rich and the info-poor. Older and sicker patients are less likely to use these portals (84). They are, however, clinically effective in managing patients with chronic disease (85) and are recommended as a strategy for narrowing the knowledge gap among patients in developing countries (86).

The National Electronic Library of Health was launched in 1998 as a project of the National Health Service in the United Kingdom (87). This initiative helps ensure that the Web will ultimately become a reliable and integral part of the care space.

Topic map functionality can be implemented as a web service (88). The XML standard for topic maps (XTM) functions as source code for web sites (28). This ensures syntactic interoperability. Ontology is needed to ensure semantic interoperability. It is also useful for evaluating site completeness for the task of answering questions. The Socratic completeness method guarantees that any logical consequence of a knowledge base can be inferred from the right questions asked in the right order (29).

From this literature review, we learn about how web sites can help users find a common ground. Users must be able to share information and understand each other. Semantic interoperability among web pages is essential.

Conclusion 10: Information is entangled with the context of its production so some restructuring of information is required for reuse.

Conclusion 11: The XML standard for topic maps can serve as source code for a web site, so reconfiguring a patient portal as a topic map based upon a sound ontology should support inference as well as semantic interoperability.

Conclusion 12: A web site can be evaluated for its completeness in the task of answering questions.

II.B.4 Document Templates

A template can be designed by a health informatician as a common point of reference, or boundary object, for joint projects with clinicians and medical educators. Health informatics graduate are trained to improve the ways physicians care for people, do research, develop health policy and introduce clinical information systems (8).

Three types of clinical information standards are needed by clinicians: document structuring standards, term lexicons and ontologies (89). There were four parts to the ENV 13606 standard for "Health Informatics -Electronic health record communication" prepared by project teams 26, 27, 28 and 29 and approved as a pre-standard in 1999. These were: extended architecture (90), domain term list (91), distribution rules (71) and messages for the exchange of information (92). Unfortunately, the adaptions to EN13606 have been ad hoc so the exchange of information between adopters has not reached semantic interoperability and the convergence of standards is an issue (93). This led to the formation of a new CEN task force, EHRCom, with the intention to harmonise the proposed new EN13606 standard with both OpenEHR (94) and the HL7 Clinical Document Architecture (95).

An electronic health record communication standard should be developed using a two-layer architecture (90,96). The dual model approach distinguishes a Reference Model, such as the HL7 Reference Information Model, for the generic properties of health record information from templates which represent the requirements of a particular user. The templates are often called archetypes (97,98). For this research, the document structuring standard, HL7 Clinical Document Architecture, supports templates (30).

The intended purpose of a template is to indicate which clinical concepts are to be captured and in what data form. The template is bound to vocabulary and this enables coding of content concurrent with data entry (26). The tension is to make them as efficient as free text, which clinicians typically use (99). Templates for progress notes, which are usually free text, improved residents' documentation accuracy for diagnoses and comorbidities (100).

The identification of minimum data sets implies the use of standard templates (101) to improve productivity(49). The coding of common concepts is made interoperable through the use of templates (102).

In previous research, we found that documentation of important clinical information is poor in the Nova Scotia health care system. This lack of documentation may be a problem of record keeping, a performance gap, a knowledge gap, or some combination of the three (103). The different models proposed for chart organization are source-oriented, problem-oriented, time-oriented, episode-oriented and pragmatic (104), and no model has emerged that is sharable by everyone (105). While template design may improve the quality of the data collected and its interpretation, it is necessary to consider the structuring of the patient record.

A practice-based analysis of patient records makes visible the form, content and function of each genre used in the clinical setting (106). There are four record structuring standards from the medical records community that a clinician may encounter.

II.B.4.1 Universal Chart Order

This is a standard that describes how to file the pages of a paper-based medical record into a chart. The chart is a physical binder with tabs that are source-oriented. The documents are filed by source and then by reverse time order. The chart order is universal because it is kept in the same order on the hospital floor as in the medical records department.

II.B.4.2 Document Tree

This is a standard that describes how the images of the pages of a paper-based medical record are filed into an electronically held chart. An example is the Horizon Patient Folder system used in hospitals in Nova Scotia's Capital Health District. The documents can be viewed by document type or by episode of care.

II.B.4.3 CEN (The European Standardization Body) Technical Committee TC251 Healthcare Informatics—Electronic Health Care Record Communication

The CEN/TC251 EN13606 standard described how the contents of clinical documents should be organized as nested containers in three layers. The first layer is structuring the record into record complexes stored as documents and sections. The second layer is structuring a complex into clinical statements. The third layer is structuring the content of a statement (91).

II.B.4.4 Clinical Document Architecture

This is a standard that describes how the nested containers of the CEN/TC251 standard can be represented as an electronic communication standard for the exchange of clinical information among trading partners. It provides a filtered view of data depending on what is relevant to the recipient (e.g., referral letter, discharge summary, personal health record) (107).

From this literature review, it is apparent that clinical documentation is confounded by the way organizations store patient information in medical records. We conclude that methods of common communication can improve the infostructure.

Conclusion 13: Use the HL7 Clinical Document Architecture standard for template design as it has shown an ability to adapt.

Conclusion 14: Help residents improve their documentation skills by introducing template use during medical training.

Conclusion 15: Address clinical pragmatic issues to ensure practical data entry and use of term lexicons meaningful at the point of data entry.

II.C Communities Of Practice

The experiential knowledge in a discipline is expressed by the employment of unique vocabulary, technology and patterns of practice (23,108). The shared practice leads to boundaries (108). Boundaries can be a source of separation and misunderstanding but they can also be areas of learning. Wenger considers boundary objects as one of the ways to bridge the boundaries. The analysis of boundary objects should determine whether they contribute to or hinder learning. "A critical boundary object is the existence of a common language that allows people to communicate and negotiate meanings across boundaries" (109). However, studies reveal a hesitation in the use of standardized terminology (68). With the CHAMP Community of Learners model, the terminology boundary objects are expected to manage a 5-way translation among perspectives.

A boundary infostructure needs to support the community's reification of its knowledge. Within communities of practice theory, boundary objects are defined as "forms of reification around which communities of practice can organize their interconnections" (110). As reifications, documents serve to anchor practice and to make the work of practice visible to the community of practice and to the outside world (111). Documents clarify boundaries and reinforce the identity of community of practice members.

Reification is a flexible concept. It is a concept used in philosophy (16,112), communities of practice ((23,111)) and topic map specifications (113). A reified statement is a statement about a fact. The process of expressing this fact in a topic map is called the reification process (79,114).

Digital documents are constructed artifacts that can be viewed through the community of practice lens. They reify practice and make visible what is attended to, and what is not (111). A clinical document, such as a discharge summary, is considered delinquent by the health administrators community of practice if it is lacking signatures, as needed for its role as a legal document (115).

The Discharge Abstract Database (DAD) is one of the key holdings of the Canadian Institute for Health Information (CIHI). Over time, it has upgraded from ICD-9-CM to ICD-10-CA for diagnoses, and from CCP (Canadian Classification of Diagnostic, Therapeutic and Surgical Procedures) to CCI (Canadian Classification of Health Interventions) for procedures (116). This upgrade identified limitations with converting records from one set of classifications to the other. Currently, CIHI's grouping methodology is designed to aggregate inpatient cases using diagnostic data coded to ICD-10-CA and procedures coded to CCI (Canadian Classification of Interventions). Administrators do not utilize physiology-based risk adjustment in their grouping methodology even though it better discriminates hospital mortality (117). The Charlson comorbidity score is commonly used for predicting length of stay and in-hospital mortality for patients with comorbid conditions (100,117,118).

As a boundary object, the concept of eHealth means different things to the individuals represented in the CHAMP Community of Learners. For clinicians, it may mean an actual physician-patient interaction via telemedicine (38). For health informaticians, it may mean the use of information technology to enable healthcare (8). For administrators, it may mean new ways of managing health information (119). For medical educators, it may mean ensuring that graduates are equipped with competencies in the use of eHealth resources (9,120,121). For patients, it may mean personal health records and portals to health information resources (2,7). It is an acknowledgement and discussion of these differences that enables a shared understanding to be formed (34).

Chronic disease programs require a flexible infostructure that can respond to the separate as well as the combined agendas of nephrologists, family physicians, nurses, patients, administrators and educators. When the infostructure is based on Web technologies, the Web browser provides a common interface for all stakeholders (7). Each user type—clinician, health administrator, patient—has different information needs. Customized channels can be provided to tailor the content to the information need.

The government imposes data collection standards for hospital encounters and physician claims (122). Physicians rarely have a strong grasp of what this might mean in data collection. The data that is electronically captured by administrative staff may not be reusable for chronic disease management needs. The categories used by different stakeholders in chronic disease vary. Administrators are naturalized to use the International Classification of Disease (ICD) nosology system, but medical educators and patients may find that categorization arbitrary. Clinical coding schemes provide a metric for semantic distance and are suited for the semantic categorization and navigation of eHealth resources (123). Hence, all categorization systems in use need to be investigated.

This thesis is written for an interdisciplinary audience, so minimal use of acronyms is respectful of the reader. However, most presenters at conferences and symposia rely on their audience's ability to interpret the acronyms used by the community of practice. A regular offering at the spring and fall symposia of the Canadian Partnership for Health Information Standards is the *Alphabet Soup of Health Information Standards* (96). The standards bodies most often referenced for this research are HL7 (Health Level 7), ISO (International Organization for Standardization), CEN/TC251 (European Committee for Standardization Technical

Committee Health Information and Communications Technology), ISO/TC215 (International Organization for Standardization Technical Committee Health Informatics), CIHI (Canadian Institute for Health Information), CHI (Canada Health Infoway) and WHO (World Health Organization).

From this literature review, we learn that boundary processes are key to learning (109).

Conclusion 16: Analyze boundary processes for pertinence and learning needs.

Conclusion 17: Identify terminology systems that are routinely used by members of the CHAMP Community of Learners.

Conclusion 18: Separate vocabulary from content so that the clinical documents can be rendered in a format that is most meaningful for the different users.

II.D Health Infostructure

Health infostructure, as defined by the Canadian Advisory Committee on Health Infostructure, has five interrelated components: organizations and people, process, information, technology and standards (124). The standards are framed using a components model (96). Its purpose is to support evidence-based decision making and health information availability (17).

The sustainability of the Canadian Medicare system requires improvements in the process of care leading to a seamless, integrated health system so clients get better service (125). Other countries have demonstrated ways to do this efficiently and at low cost. An example is the service chain concept implemented in Finland using clinical document repositories as the major eHealth resource (126,127).

The standards development organizations play lead roles in health infostructure development. These roles include: "developer, consensus builder, approver, maintainer and conformance/compliance tester" (96). Leaders of four major initiatives in Canada, United States, England and Australia have decided to collaborate more closely on common standards for seamless exchange of information (128).

Canada Health Infoway is a not-for-profit corporation formed in 2000 and charged with the task of delivering on the tactical plan for Canada's Health Infostructure (124,129-131). The Infoway Standards Collaborative (131) is responsible for the implementation support, maintenance conformance and education for electronic health record standards developed by Canada Health Infoway. Many of these standards follow the message development model, an international standard (92).

Colleagues from the European Commission and the United States formed a fruitful partnership that produced the electronic health record architecture standards (132) and SNOMED CT[2]. The establishment of SNOMED CT from the merger of the United Kingdom's Clinical Terms Version 3 (formerly known as the READ Codes) and SNOMED RT (reference terminology) (133-135)holds promise for enabling clinicians to more robustly document clinical work. READ Codes were an established coding system in Europe (136). The coding of clinical work that is needed for epidemiology, claims and performance management could, ultimately, be derived from more granular documentation represented using SNOMED CT (137).

Health infostructures in Australia and New Zealand helped ensure wide dissemination of electronic health record systems for primary care providers (138). An Australian infostructure component is the *General Practice Data Model and Core Data Set* (139).

From a pragmatic perspective, the most effective activities would be to focus on those components that are common to all infostructure models and are described as (140):

1. a common data model
2. terminology management model
3. a formalism for queries and expressions
4. a formal method for describing process flow/work flow
5. a taxonomy of services or actions that can be invoked by steps within a clinical guideline

[2] http://www.snomed.org/snomedct/what_is.html

Three factors that may accelerate the convergence to global standards for a health infostructure are: 1) the Web as a health knowledge resource for citizens (31,132); 2) repositories of electronic resources to support evidence based medicine (132,141,142); and 3) the advent of eXtended Markup Language (XML) and Semantic Web technologies to deliver knowledge resources (22).

From this literature review, we learn about ways to improve adoption of a boundary infostructure.

Conclusion 19: Use common standards that facilitate seamless exchange of information.

Conclusion 20: Consider the web as an integral part of the care space and exploit Semantic Web tools for pragmatic construction of a boundary infostructure.

II.E Medical Informatics Competency In Medical Education

One way to enable medical school graduates to acquire medical informatics competencies is through integration of curricula (143). Other ways are through exposure of medical students to practices where clinicians use computers in daily tasks (45). There is no denying that clinicians need to become more proficient in computer use While workshops and continuing medical education programs can facilitate skills acquisition (144), according to situated learning theory, this learning should take place in a professional context (145,146).

The CanMeds 2005 project of the Royal College of Physicians and Surgeons of Canada serves as a framework for medical educators. The competencies that are pertinent to the development of pragmatic proficiency in the production of clinical documents used for communication and learning include (147):

2.4. Employ information technology appropriately for patient care

3.5 Demonstrate effective clinical problem solving and judgment to address patient problems, including interpreting available data and integrating information to generate differential diagnoses and management plans

5.1. Maintain clear, accurate, and appropriate records (e.g., written or electronic) of clinical encounters and plans

5.3. When appropriate, effectively present medical information to the public or media about a medical issue

From this literature review, we identify opportunities to encourage clinical adoption of a boundary infostructure through education.

Conclusion 21: Utilize templates to help clinicians in training gain proficiency in clinical documentation and electronic communication.

Conclusion 22: Motivate learning through use of real examples in a professional context.

II.F Nosology, Nomenclature And Classifications

Concepts in medical nomenclature are organized into hierarchies. The hierarchical structures are composed of propositions (objects and their properties) that reduce data entry complexity yet preserve precision. The logic-based definition of a concept creates a fundamental unit of information which preserves the necessary detail (fine granularity) to unambiguously meet the need for precision and specificity (134,148,149). It is the unique construction of propositions as fundamental units that permit complex and clinically valuable information to be recorded and retrieved while avoiding redundant data entry. A hierarchical structure allows propositions to be both classified and utilized with efficiency (150).

Nosology is the branch of medical science dealing with the systematic classification of diseases and the naming of clinical concepts characterized by a disease. An effective nosological system should serve the interests of data collection for multiple purposes as well as the reasoning that leads to a "nosos" (disease) (151). Comprehensive health information should meet the need of marker projects and allow health workers to learn about the relationship between activities and results (152). Diagnosis informs treatment and provides the clinician with a way to predict prognosis.

Nosology is far more than a matter of terminology, as it also points out scientific controversy. An example is *Dementia with Lewy Bodies* (153), a condition first described in the literature forty years ago but not included in the World Health Organization's ICD10 coding system until the 2006 release (154). The caregivers of patients with this disorder usually go to Alzheimer's disease support groups but from a pathological perspective the disorder is deemed the same as Parkinson's Disease but in a different location (153).

The two nosology systems considered to be the foundation for electronic data interchange in the US are 1) the International Classification of Disease (ICD-9-CM) and 2) the Systematized Nomenclature of Medicine Clinical Terms (SNOMED CT) (155). Studies have not answered the questions about the efficacy of available clinical vocabularies in coding family practice (156). They have suggested that SNOMED is the most appropriate coding system for the computer representation of clinical trials (72).

Different versions of ICD are used in Canadian clinical information systems. The International Classification of Disease Tenth Version, Canadian modification (ICD-10-CA) is used for communications between hospitals and the Canadian Institute for Health Information (CIHI). There is no one-to-one mapping between the two versions of the ICD system. CIHI published the results of a mapping from ICD-9-CM to ICD-10. It showed that, of a total of 13,600 ICD-10 codes, 50.8% were more specific than the ICD-9-CM codes, 31.5% were as specific, and only 11.5% either were less specific or could not be compared (116).

The three character codes are mandatory for reporting to World Health Organization, but member countries can expand the codes further. The ICD-10-CA uses up to six characters to express a diagnosis (157). Within all blocks, some codes are reserved for conditions not specified elsewhere in the classification (154). Version 2006 of ICD-10-CA replaced Version 2003, and has 317 new codes and 1046 deactivated codes (157).

SNOMED, in development for over 35 years, is widely used in Quebec and in laboratory information systems throughout Canada (133,158-160). It promotes precise communication among physicians. Natural language processing tools have been used to encode physician's statements to SNOMED in experiments (161) and in practice (158). SNOMED 3.5 consists of 156,965 terms and codes along 12 axes[3]. Representation of complex terms that do not exist in SNOMED is accomplished through the post-coordination of terms from multiple axes (73).

SNOMED CT is organized into three files: concepts, descriptions and relationships. Each SNOMED CT concept has a numeric code and a "legacy code", which is the SNOMED International alphanumeric code format. SNOMED CT contains approximately 350,000

[3] http://www.snomed.org/about/perspectives.html

concepts organized into 18 hierarchies and approximately 1.45 million semantic relationships (58).

While there do not appear to be any SNOMED CT implementations in Canada (5), it is recommended for use by Canada Health Infoway for new projects (162). Common terminology standards are critical to the achievement of Infoway's goal of an interoperable pan-Canadian Electronic Health Record and for seamless exchange of information for public health (128). Infoway's rationale for choosing SNOMED CT was based on benefits to healthcare providers, clinical administrators and patients of a more complete and comprehensive code set. These attributes should lead to more accurate records that improve patient safety, reduce test duplication, support real-time planning and clinical decision support (163).

The labeling of clinical problems requires a nomenclature. Undocumented patient information may reveal a knowledge gap or a performance gap (103,164). Each specialty evolves its knowledge base and expresses the different perspectives using vocabulary that is meaningful to its members (165). A nosology system may be developed as a boundary object to provide a method for common communication. An example is the Surgical Nosology in Primary-Care Settings that provided a bridge between primary and surgical specialist care for the task of classifying patients for referral. The specialists defined the anatomical structure and the primary caregivers described the problem (166).

There are two major types of classification systems: enumerative and analytico-synthetic.

Enumerative classification attempts to assign headings for all subjects of the past, present and anticipatable future and enumerate them. The ICD is enumerative. The ICD has been evaluated as a boundary object and deemed to be a pragmatic construction. It is "tailored to the degree of granularity that can be realistically achieved" (80).

Analytico-synthetic classification analyzes a subject into different facets and then synthesizes it into a semantic definition following prescribed rules. Ranganathan designed a library scheme based on the analytico-synthetic method, called the Colon Classification. He divided the construction of a classification into three planes of work: analyze a subject into its component parts; choose appropriate terminology; and express component parts by means of notational device (167). A relational structure implemented with a faceted query language (168) may provide the basis for a common retrieval language as suggested by Ranganathan. Since topic maps can be populated from tables (28) and have been successfully used for accurate searching of clinical data (70,169), they may provide the basis for implementing facet-based retrieval. Chronic disease management standards, such as the HL7 Canadian Chronic Disease Management specification (5), publish the specifications as tables. They specify markers of disease progression and risk factors that are facets for classifying patient cases.

An analytico-synthetic classification approach to terminology requires the analysis of concepts into their atomic components and the synthesis of knowledge through concept definitions that depend on relating one concept to another. For SNOMED's core terminology classification, each concept is represented using description logic statements to denote its essential characteristics (134). This approach enables comparison among concepts that are decomposed into primitives and inferencing to determine relationships based on facts expressed in concept descriptions.

The UMLS Metathesaurus was constructed using an analytico-synthetic method. UMLS now contains over 1 million concepts and 5 million unique concept names from more than 100 source vocabularies. Some of these sources are knowledge bases which support inferencing. UMLS contains co-occurrence data (disease/finding pairs) from the AI/RHEUM knowledge bases (69). The AI/RHEUM clinical decision support system was designed to support diagnostic reasoning for a chronic disease, rheumatoid arthritis (70). It classified patient data into a hierarchical tree.

When the intended use of a terminology is aggregation and statistical classification, then an enumerative systems, such as ICD, is favored (63,77). When the intended use is clinical care, an analytico-synthetic classification system, such as SNOMED, is favored because it is capable of integrating clinical decision support with patient information (72,170), representing nursing work (171) and representing clinical statements (134). SNOMED and UMLS support a mapping of concepts to ICD-9-CM system (172).

Classifications serve many functions. As an example, the Primary Renal Diagnosis classification is used for appointment scheduling in the Nephrology Department, Capital Health District Authority and for registering patients needed renal replacement therapy with the Canadian Organ Replacement Register. The classification is based on international disease registry work (173) and the Primary Renal Diagnosis codes are represented in SNOMED CT because they existed in the Read Classification system that was subsumed in SNOMED CT. There is a mapping from Primary Renal Diagnosis codes to ICD-10-CA codes and it reveals how the diseases are framed differently (173,174). The nephrologists balk at using ICD-9-CM and ICD-10-CA in their daily work because these classifications put most of their work into a miscellaneous category. The framing of a disease reveals a cultural history (175) and consequences (176).

From this literature review, we learn that all classification systems are boundary objects (176); inferencing is facilitated by analytico-synthetic classification (168); and benefits will accrue to multiple communities of practice through use of SNOMED CT in infostructure (163). This has the following implications for this research:

Conclusion 23: Choose SNOMED CT as the principal terminology system in the infostructure.

Conclusion 24: Use either SNOMED CT or UMLS as a "switching language" for translation to ICD.

Conclusion 25: Utilize semantic definitions that follow prescribed rules so that concepts can be expressed by their facets.

Conclusion 26: Take an analytico-synthetic approach to content representation to facilitate inferencing.

II.G Ontology Creation

Ontological tools are required for explicit representation of the subject matter of a domain. Individuals in the CHAMP Community of Learners model need term definitions, relationships and pragmatic information, such as advice and user manuals, to do their work and train newcomers. The representation of domain knowledge that is explicit can be achieved through use of a standard vocabulary based on an ontology (61). An ontology supports knowledge reuse, exchange of data between systems, and description of the classes on which problem-solving methods operate.

Terminology systems provide a representation vocabulary for the ontology. There are three generations of coding systems. First generation is monoaxial classification systems, such as the World Health Organization's ICD. Second generation is vocabularies that take a multiaxial approach and support combining terms to represent a complex concept. SNOMED is an example of a second generation coding system that can serve as an indexing language for ontologies. Third generation is concept reference models, such as the GALEN system, which can be used as a basic ontology in knowledge-based systems (68).

Topic maps are a tool for the formal description of a conceptualization. An ontology is required to achieve semantic interoperability (23). The strategy of representing clinical activity from different perspectives will require integration of the different views of a concept. The semantic indexing of clinical cases requires an ontology that enables the medical educator to determine case similarity. A well formed clinical concept can be expressed as an archetype. An archetype is a way to configure the data structures to produce a more concrete clinical model specific to the domain of concern (98,177). Once this is accomplished, the archetypes can be associated as a subject reference for clinical concepts in a topic map. The ontological representations of concepts in thesauri, hierarchical classification systems and analytico-synthetic classification systems can be represented in topic maps (178). The fixed vocabularies of classifications is represented using topic map design patterns (179).

The Semantic Web framework has three main components (22): XML, information about data structures using resource description framework or topic maps and a web ontology language. The current Semantic Web tools are not considered capable of supporting reasoning, or determining completeness. Other standards are needed for logic. These include using conceptual graphs to represent knowledge from medical terminology (173,174) and Access-Limited Logic to determine logical relevance and completeness for the task of answering a query (29).

From this literature review, we learn about the heterogeneity of ontology in biomedical applications.

Conclusion 27: Utilize existing ontology from nosology systems to establish conceptual context.

Conclusion 28: Create an ontology that enables semantic interoperability when implemented in a topic map.

II.H Pragmatic Proficiency And Competency

Newcomers to the medical professional learn the language of care as part of the process of becoming a member of that community. Medical students encounter this "medical English" in case write-ups and experience it in the care setting. Residents in a specialty discipline practice it when they create clinical documentation for the medical record of a patient who receives hospital-based care (180,181). The communication proficiency of clinicians is evaluated from recordkeeping and the documentation produced (120,182,183).

Pragmatic communication is defined by Grice and stated in his Cooperative Principle: "Make your conversation such as is required, at the stage at which it occurs, by the accepted purpose or direction of the talk exchange in which you are engaged" (24). His conversational maxims—quantity, quality, relevance and manner—provide the rules. From a cooperative perspective, the attributes of a communication should be clear, concise, correct, complete and conform to commonly agreed-upon standards.

Clinicians using different words should have a common understanding of what those words mean. To ensure pragmatic competency, the same word should mean the same thing to all readers. If words can mean different things to different people, we end up in an *Alice in Wonderland* (184) world where word meanings are just what someone chooses them to mean. Subject references derived from actual patient information will provide an opportunity for learners to experience how terms are used in the context of care.

Boundary object analysis allows us to become aware of the translations that are made among the communities of practice and through this analysis, ways of improving pragmatic proficiency to facilitate pragmatic competency. It should be possible to enrich a statement through awareness of its context so that pragmatic competency is improved (32).

Three properties of humans' cognitive capabilities are recognition of different levels of information, categorization of semantic information and limitation in processing information. This is recognized in city design, where different elements can be quantified by means of Shannon's theory of information and by typology (height, land use, architectural style) (185). These imply that the pragmatic meaning of information can be improved by document and terminology structure.

From this literature review, we learn about ways to evaluate the boundary infostructure.

Conclusion 29: Use Gricean analysis to evaluate the quality of a clinician-to-clinician communication.

Conclusion 30: Utilize knowledge embedded in terminology systems for pragmatic enhancement of the contents of the Clinical Document Repository and the Patient Information Repository.

Conclusion 31: Seek feedback from users on usefulness and usability of boundary infostructure components.

II.I Summary Of Conclusions

This thesis investigated if a constructed boundary infostructure led to clinical communications that were more pragmatic than those completed using existing infostructures. The conclusions reached in the literature review informed the methods chosen for the six research objectives. The association between the research hypotheses and the literature review conclusions are given in Table II.1.

Table II.1 Research Hypotheses And Literature Conclusions

Hypothesis	Conclusion
Hypothesis 1. Data Quality Improvement	6: Maintain clinical narrative as this helps establish context. 13: Use the HL7 Clinical Document Architecture standard for template design as it has shown an ability to adapt. 14: Help residents improve their documentation skills by introducing template use during medical training. 21 Utilize templates to help clinicians in training gain proficiency in clinical documentation and electronic communication. 29 Use Gricean analysis to evaluate the quality of a clinician-to-clinician communication.
Hypothesis 2. Clinical Pragmatics	10: Information is entangled with the context of its production so some restructuring of information is required for reuse. 19: Use common standards that facilitate seamless exchange of information. 20: Consider the web as an integral part of the care space and exploit Semantic Web tools for pragmatic construction of a boundary infostructure.
Hypothesis 3. Usefulness and Usability	1: Use standardized forms or templates to improve productivity of users and clarity of electronic health records. 3: Use a common data standard to lessen impact of vendor volatility. 5: Focus on systems that are useful, usable and used to improve the lives of physicians and their patients. 11: The XML standard for topic maps can serve as source code for a web site, so reconfiguring a patient portal as a topic map based upon a sound ontology should support inference as well as semantic interoperability. 12: A web site can be evaluated for its completeness in the task of answering questions. 30: Utilize knowledge embedded in terminology systems for pragmatic enhancement of the contents of the Clinical Document Repository and the Patient Information Repository. 31: Seek feedback from users on usefulness and usability of boundary infostructure components.
Hypothesis 4. Constrained Terminology	7: The classifications should be pragmatic constructions that are vague enough to be common. 15: Address clinical pragmatic issues to ensure practical data entry and use of term lexicons meaningful at the point of data entry. 17: Identify terminology systems that are routinely used by members of the CHAMP Community of Learners. 18: Separate vocabulary from content so that the clinical documents can be rendered in a format that is most meaningful for the different users.

Hypothesis	Conclusion
Hypothesis 5. Commensurability of Different Classifications	8: The UMLS contains a hierarchical classification of patient data for mapping from patient data to medical knowledge in a chronic disease knowledge base, AI/RHEUM, that could serve as an example of a tree representation of document sections and entries. 23: Choose SNOMED CT as the principal terminology system in the infostructure. 24: Use either SNOMED CT or UMLS as a "switching language" for translation to ICD. 25: Utilize semantic definitions that follow prescribed rules so that concepts can be expressed by their facets. 26: Take an analytico-synthetic approach to content representation to facilitate inferencing. 27: Utilize existing ontology from nosology systems to establish conceptual context.
Hypothesis 6. Common Ground	2: Educate physicians via their social networks to have a positive impact on clinician adoption of electronic health records. 4: Recognize the multifaceted needs of users from different communities of practice. 9: The subject references can elaborate the contents of the Patient Information Repository and the Clinical Document Repository, leading to improvements in pragmatic competency. 16: Analyze boundary processes for pertinence and learning needs. 22: Motivate learning through use of real examples in a professional context. 28: Create an ontology that enables semantic interoperability when implemented in a topic map.

Chapter III: Overview Of Topic Maps

Topic maps were used for knowledge representation through semantic associations. They can explicate implicitly coded knowledge (28). This helps with concept formation, which is a process of generalization from examples (1).

Topic maps were proposed as a common language for context (186). To provide users with information that applies to their particular situations, the software must be aware of the user's context. In this research, the context of use is from the perspective of a user's community of practice.

It was hypothesized that topic maps could function as the infostructure "glue" to mediate learning at the boundary between and among communities of practice. To test this hypothesis, we first considered what topic maps were and how they might function as the infostructure glue.

III.A Topic Maps Standard

The International Standards Organization topic map standard, ISO 13250, is composed of four parts (113): ISO 13250-1: Topic Maps--Overview and Basic Concepts; ISO 13250-2: Topic Maps--Data Model; ISO 13250-3: Topic Maps--XML Syntax; and ISO 13250-4: Topic Maps--Canonical XML Syntax. The topic map notation is defined as a SGML (Standard Generalized Markup Language) Architecture and the XTM (XML for Topic Maps) interchange standard is compatible with the family of XML standards. It was introduced for ballot in 1999 with the official draft of the XTM 2.0 syntax specification dated 2006-06-19[4]. It is considered a stable for use standard.

Topic maps incorporate a powerful definition of subject. Their definition of subject is "anything whatsoever, regardless of whether it exists or has any other specific characteristics, about which anything whatsoever may be asserted by any means whatsoever" (187). This definition is powerful because it enables a single representation to handle the ontological

[4] http://www.isotopicmaps.org/sam/

information about the information objects, how the subjects are used to classify the information objects, the constructs applied to index the information objects, the user contexts and the information objects themselves. Subjects are the real world thing that the topic stands in for.

Topic maps formally declare the identity of a topic's subject using a mechanism based on URI (Uniform Resource Identifier). Topic maps allowed users to assert relationships and thus aid in interpretation and knowledge sharing.

The declarative part of a topic map is itself a topic map. A tool, such as Ontopoly from Ontopia[5], enables the manual creation of topic maps based on a variety of ontologies, such as the thesauri ontology (179) and the case-based reasoning ontology (189). Topic map design patterns provided a means for organizing information in a consistent manner (179).

Topic maps provide a superimposed view of an information set, analogous to a navigation map. They allow us to use concepts and relations among concepts to express statements about the way we organize subject matter. From the mathematical perspective, it is a "deterministic formal system of elements and sets of elements that models conversation and records knowledge" (188).

The product of topic map configuration is an ontology and its XTM schema. The process requires the definition of the topic, name, association, association role and occurrence types that will be available to creators of the instance topics.

Importing independently developed nosology systems, classifications and thesauri into topic maps ensures that the resulting ontology-based topic map has been vetted by the community of practice that produced it.

III.B Topic Maps As The Infostructure Glue

The subject-based techniques that are commonly applied in information architecture solutions include thesauri, faceted classification, categories and ontologies (178). The fixed vocabularies of these subject-based techniques can be used as a topic map vocabulary. Through extension

[5] http://www.ontopia.net/solutions/ontopoly.html

of this idea, the topic map could represent the constrained terminology in the boundary infostructure despite the differing information architectures used in the boundary objects.

Topic maps are powerful because they are able to express all terms in the boundary objects in a single representation. Topic map design patterns can be applied to represent the approaches used for information organization which are common in information architecture and library science (179). The constrained terminology in the boundary infostructure plays a role as metadata to provide information about the objects in the boundary infostructure. The metadata is represented in different types of boundary objects. The information organization of boundary objects are hierarchical categorization for enumerative classification systems (ICD-9, ICD-10-CA, CCI, CCP and ATC); faceted classification for analytico-synthetic classifications (SNOMED 3.5, SNOMED CT and HL7); and, thesauri (UMLS). A modular approach to topic map construction could use the topic map design patterns approach (179) to represent the declarative information.

Topic maps can merge the different ontological expressions of knowledge embedded in classification systems and standards. Such a topic map can facilitate comparison of different constructions placed on the same set of clinical data by members of different communities of practice. Perspectival differences among communities of practice arose, in part, from differences in their ways of classifying concepts.

In the CHAMP Community of Learners model, members of the different communities of practice have a user context. This user context was a faceted view. The scope feature in topic maps provided a mechanism for assigning user context to information resources. In this way, the topic map could consider the different contributions and the preferred boundary objects for classifying concepts. Clinicians provided documentation on the medical encounter with a patient. Health informaticians provided health information standards, terminology systems and coding rules. Administrators applied the coding rules to the clinicians' documentation. Medical educators worked at the boundary between theory and clinical practice, and generate prototypical cases to teach about problems and solutions. Patients were at the centre, since it is their story that was being documented.

The topic map provided a common interface to illustrate the different classifications used by these stakeholders. The set of perceptions were needed to get a complete picture of an information object, such as a clinical document. It would be differently constituted based on the coding that was done. The idea of deliberately constructing a boundary infostructure so that it explicitly recognized "the differing constitution of information objects within the diverse communities of practice that share a given infrastructure" came from Bowker and Star (12).

The same technology, topic maps, could represent the objects in the boundary infostructure. The objects were the clinical documents in the Clinical Document Repository and the webpages in the Patient Information Repository. Topic maps could connect across heterogeneous structures. The entries in the Clinical Document Repository were expressed in XML and the webpages in HTML. Topic maps were an XML-based standard, as were HL7 CDA (Clinical Document Architecture), the standard used for objects in the Clinical Document Repository.

The three-layer model for subjects, structures and context shown in Figure III.1 could be represented as a topic map because of the ability to navigate across the layers.

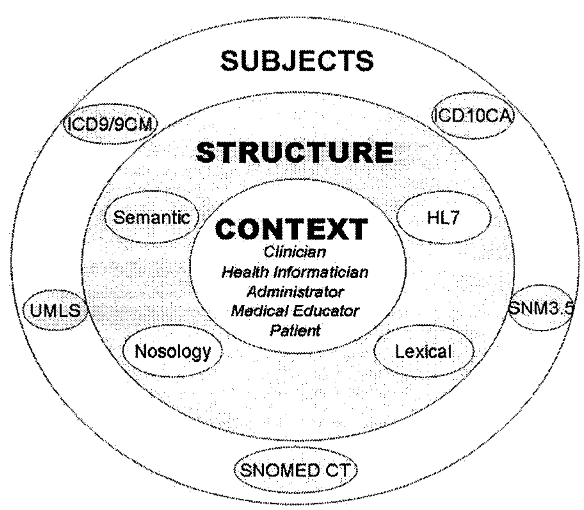

Figure III.1 Three-layer Model As A Topic Map

The ontology process is depicted in Figure III.2. The first stage was to run the three studies described in Chapters IV, V and VI, and use the outputs from those studies as input to the ontology process. The outputs were identified subjects for the topic map and reified examples stored as objects in the Clinical Document Repository and the Patient Information Repository. The studies gathered empirical data on medical language used by members of the CHAMP Community of Learners. The second stage of the ontology process was to explicitly identify the subject matter in clinical terminology systems. The third stage was to learn how the subjects were categorized in classification systems and HL7 information architecture standard. The fourth stage was to represent the categorization knowledge using the topic map information architecture standard, so that patient information could be interpreted in a user context.

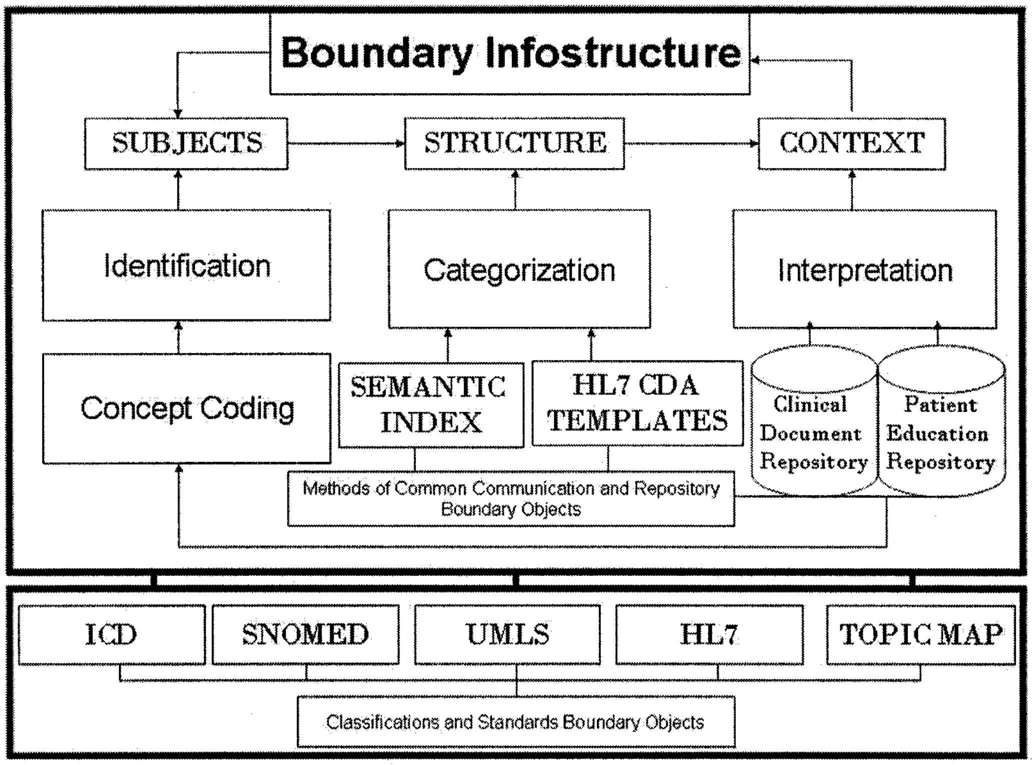

Figure III.2 Ontology Process For A Boundary Infostructure

The semantic index for each entry in the Clinical Document Repository could be expressed as a topic map (Figure III.3). The merging of the topic maps for subjects, structure and context with the semantic index topic map facilitated semantic interoperability among electronic resources: ontology, semantic index and Clinical Document Repository.

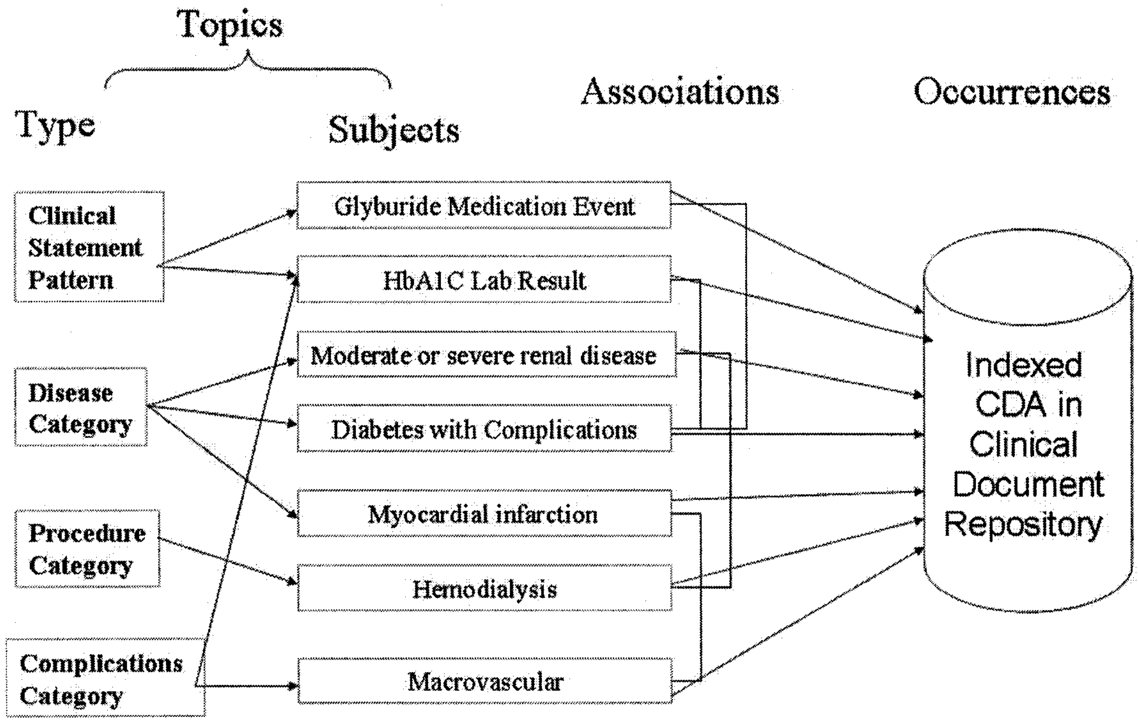

Figure III.3 Semantic Index For Clinical Document Repository As A Topic Map

The semantic index for each webpage entry in the Patient Information Repository could also be expressed as a topic map (Figure III.4).

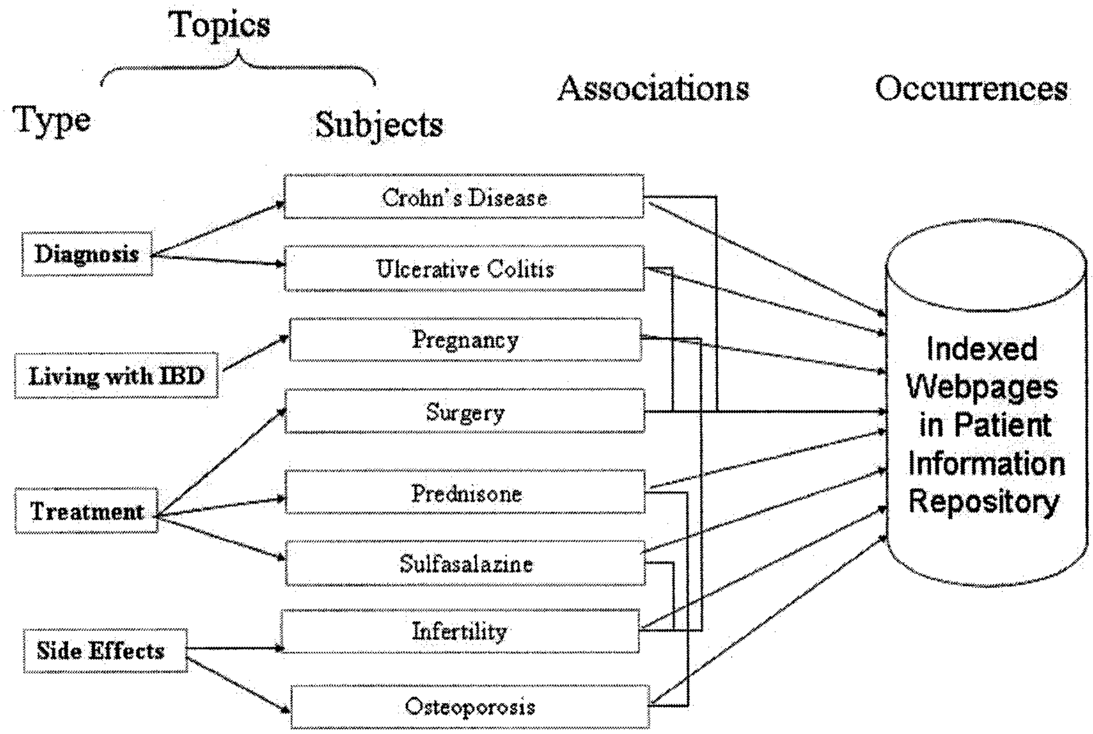

Figure III.4 Semantic Index For Patient Information Repository As A Topic Map

By binding the information together so that it can be navigated in multiple ways, the topic map functions as the glue for the boundary infostructure.

III.C Populating The Topic Maps From Research Studies

The electronic health resources produced in three studies were the inputs to the ontology process and the creation of the topic maps for Chronic Kidney Disease and Inflammatory Bowel Disease. The studies were:

1. Transcription Versus Electronic Health Record Templates for Chronic Kidney Disease Discharge Summary. The electronic discharge summaries were produced by clinicians using direct data entry via an HL7 Template and by clinicians using a dictation and transcription system. The study was conducted in 2006

2. Utilisation de topic maps et HL7 dans CIRESSS. The electronic discharge records of anonymized patients were generated from queries posed by health informaticians to a clinical data warehouse containing hospital data. The study was conducted in 2006.

3. HealthInfoRx™: Lifelong Learning for Chronic Disease Patients and Their Caregivers. The electronic webpages were produced by clinicians, health informaticians, medical educators and patients. Study investigators recruited 76 patients from the Inflammatory Bowel Disease Clinic, Nova Scotia. The study was conducted from February 2002-March 2004 (32).

Chapter IV: Study One: Transcription Versus Templates For Discharge Summary

This study was conducted to test the data quality improvement, clinical pragmatics, and usefulness and usability hypotheses. The first phase was the data gathering from the research study itself. The second phase was the application of the ontology process for the first version of the chronic kidney disease boundary infostructure. This version was augmented with findings from the Clinical Data Warehouse Discharge Records study described in Chapter V.

IV.A Study One Phase One

The title of this study was *Transcription Versus Electronic Health Record Templates for Chronic Kidney Disease Discharge Summary.* The author and a nephrologist, Dr. S. Soroka, were co-investigators for study. The study question was, "*Does use of the HL7 Template for Chronic Kidney Disease Discharge Summary lead to discharge summaries that are more complete and contain more of the essential data elements than those completed using the Dictation and Transcription System?*"

It was hypothesized that we could improve the quality of Discharge Summaries for chronic kidney disease patients by using a template to prompt medical residents to enter relevant data when documenting care.

The HL7 Template for Chronic Kidney Disease Discharge Summary was the intervention. The template featured a clinical calculator, information lookup (primary renal diagnosis, co-morbidity diagnosis and lab tests) and medication query using the Nova Scotia Formulary. The participants were randomized to start with transcription followed by template or template followed by transcription. The information source was the paper chart of a real patient for a particular hospital stay. Clinicians created a coded electronic discharge summary compliant with the HL7 Clinical Document Architecture (CDA) Release 2.0 specification and a dictated discharge summary for transcription by secretarial resources. Data interpretation was supported by links to SNOMED CT concept descriptions and Canadian Institute for Health Information (CIHI) discharge abstract. The discharge summaries were scored for their pragmatic qualities and participants were asked for feedback on their experience. Electronic discharge summaries and the chart entries they referenced were stored as CDA examples in the

Clinical Document Repository. The information was then rendered in different forms depending on user context in the CHAMP model.

The Dictation and Transcription System was the standard method for creating discharge summaries in the hospital. The clinician dictated information onto a tape cartridge using a dictating machine, and the contents of the tape were transcribed by secretarial personnel. Guidance for this task was provided by the *Discharge Summary Training Manual.* It outlined the purposes and specifics of discharge summaries. It was published by the Department of Medicine Education Office, Dalhousie University and Queen Elizabeth II Health Sciences Centre.

The CKD Template for the electronic discharge summary was the intervention. The template was for data entry to produce an XML file based on the HL7 Clinical Document Architecture specification. It supported concurrent coding to HL7, SNOMED 3.5, SNOMED CT and ICD-10-CA. The concurrent coding was accomplished using lookup lists for diagnosis, co-morbidity and lab result; drop down menus for physician specialty, sex, health status, family history of disease, race, vital signs, medication route, medication frequency and medication status; and a clinical calculator for chronic kidney disease stage based on the glomerular filtration rate. There were web links to the ICD10 online database for diseases categorized by the World Health Organization[6] and to the online Nova Scotia drug formulary[7] for medications. Guidance for this task is provided by the study's *Chronic Kidney Disease Discharge Summary User Manual*, produced by the author.

A study participant can review his discharge summary and link to terminology knowledge that was associated with each coded field. Each coded field was associated with a SNOMED CT code. The terminology knowledge was available as a web page generated from the CLUE Browser[8] for SNOMED CT. The terminology information was the concept with its English description and semantic type. The concept was defined using description logics to relate the concept to other concepts, and to its place in the hierarchy or hierarchies where it was

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[6] http://www.who.int/classifications/apps/icd/icd10online/
[7] http://www.gov.ns.ca/health/pharmacare/formulary.asp
[8] http://www.clinical-info.co.uk

represented. SNOMED supports multiple hierarchical relationships, whereas ICD supports a single hierarchical relationship.

IV.A.1 Materials And Methods

The study population was those medical trainees listed on the Nephrology House Staff Master Schedule. The inclusion criteria were: Trainee is eighteen (18) years or older; Trainee is registered as a clerk or resident at Dalhousie University Medical School; Trainee is willing to take part in this study, including signing the Consent Form after carefully reading it. There were no exclusion criteria. Trainees were consented by medical educators in the Division of Nephrology, Department of Medicine, Dalhousie University. Efforts to recruit trainees to the study included presentations to the study population by Dr. Soroka on July 3, 2006 and by this author on August 24, 2006, at the invitation of the Postgraduate Education Coordinator.

See Appendix C for Recruitment Questionnaire, Feedback Questionnaire and Quick Start Guide used in this study, Transcription versus Electronic Health Record Templates for Chronic Kidney Disease Discharge Summary.

A standardized 72-page patient chart was used by all participants to produce their version of a discharge summary. The 69-year old male patient had been admitted for assessment of renal insufficiency. His co-morbidities included diabetes mellitus and hypertension. Over 70% of the chart pages contained handwritten information, so generation of an electronic discharge summary without human intervention was not an option.

The study design was randomized within-subject. The study participant was randomized to either "dictation first; template second" or "template first; dictation second".

The intervention was a HL7 Template for producing an electronic Chronic Kidney Disease Discharge Summary through direct data entry by study participants. The methodology was:

1. to design a template based on HL7 CDA specification, feedback from medical educators and residents, and beta-testing of the template by experienced clinical staff
2. to create an infostructure for concurrent coding at the time of documentation

3. to test whether use of the template led to Discharge Summaries that were more complete and contained more essential data elements than those completed without the use of the template
4. to score the quality of the discharge summary produced using dictation and transcription versus the HL7 template using a scoring instrument designed by van Zanten et. al. (203) (Figure IV.1) and scored by medical educators
5. to ask the trainees to provide feedback on their experience of using the two methods and to analyze their response
6. to demonstrate reuse by transforming content in the electronic discharge summary into a Canadian Organ Replacement Register form and a patient's longitudinal health record entry

Discharge summary reports were an example of an *ideal type* of boundary object. They were produced as an abstraction from the information in the patient chart and were treated as a summary for multiple purposes. The discharge summary was a reification of clinical knowledge and practice.

Score Sheet

Patient Name________________________
Admission Date_______________________
Discharge Date_______________________

	Inappropriate Low				**Appropriate High**
Admitting Diagnosis	1	2	3	4	5
Discharge Diagnosis	1	2	3	4	5
Lab Data -completeness	1	2	3	4	5
-brevity	1	2	3	4	5
Discharge Recommendations	1	2	3	4	5
HISTORY	**Low**				**High**
Completeness	1	2	3	4	5
Conciseness	1	2	3	4	5
Brevity	1	2	3	4	5
PHYSICAL	**Low**				**High**
Completeness	1	2	3	4	5
Conciseness	1	2	3	4	5
Brevity	1	2	3	4	5
HOSPITAL COURSE	**Low**				**High**
Completeness	1	2	3	4	5
Conciseness	1	2	3	4	5
Brevity	1	2	3	4	5
OVERALL IMPRESSION	**Low**				**High**
Length	1	2	3	4	5
Structure	1	2	3	4	5
Language	1	2	3	4	5
Global Rating	1	2	3	4	5

Figure IV.1 Discharge Summary Score Sheet

The methodology for evaluating pragmatic proficiency was Gricean maxims for the Cooperative Principle—quantity, quality, relevance and manner. The clinicians created the discharge summary. It was a report of activities (e.g., laboratory results, medication events, procedures) documented during the patient journey—admission, course in hospital, discharge. The HL7 Template for the Chronic Kidney Disease Discharge Summary was designed to monitor biochemical abnormalities and capture the reason for treatments associated with the progression of kidney disease as expressed in the literature (190,199). The template was based on HL7 Clinical Document Architecture Release 2.0, where the electronic discharge summary would be viewed as a collection of statements.

To evaluate discharge summaries for their adherence to the maxims associated with Grice's Cooperative Principle, two standards specifications were employed. These were the HL7 Clinical Statement and the Western Canada Chronic Disease Management Infostructure Initiative.

The working definition for the HL7 Clinical Statement concept is (205):

> *An expression of a discrete item of clinical (or clinically related) information that is recorded because of its relevance to the care of a patient;*
>
> *Clinical information can be expressed with different levels of granularity and the extent and detail conveyed in a single statement may vary;*
>
> *To be regarded as a clinical statement a concept must be associated with a patient in a manner which makes clear 1) its temporal context; 2) its relationship to the patient; 3) in the case of an observation, its mood and presence, absence or value; 4) in the case of a procedure, its mood and status.*
>
> *This clarity may be achieved by 1) explicit representation; or 2) implicit application of defaults ONLY where explicitly modeled rules state the appropriate defaults.*

The HL7 Clinical Statement definition was applicable to boundary object design because it recognized that clinical information could be expressed with different levels of granularity.

The Western Canada Chronic Disease Management Infostructure Initiative (WHIC-CDM) was applicable to the clinical domain for this study, because it constrained the specification to Diabetes, Hypertension and Chronic Kidney Disease (5). The timeframe for the WHIC-CDM was March 2004-March 2006. The timeframe for the Transcription Versus Templates for Discharge Summary research was December 2004-August 2006. The two projects overlapped.

The method adopted for data entry into the HL7 Template was concurrent coding for diagnoses, lab results, vital signs and medication events. The coded statements were expressible as HL7 Clinical Statements.

The method adopted for evaluation was to determine to what extent the trainee had captured the markers of disease progression for diabetes, hypertension and chronic kidney disease. The clinical data that expressed markers of disease progression and complications of chronic disease were specified in the WHIC-CDM specification. Markers of disease progression and complications of chronic disease were used in the generation of a patient's journey, similar to the journey for a prototypical diabetes patient[9].

Clinicians were asked about their experience using an electronic template to produce a discharge summary. The HL7 Template for the Chronic Kidney Disease Discharge Summary was created as a boundary object. It was evaluated for its pragmatic dimensions of clarity, completeness, relevance and usefulness.

IV.A.2 Document Structure

The idea behind the HL7 Clinical Document Architecture was that the clinical document made a clinical statement, and HL7 could be viewed as a language with a syntax, grammar, and rules for statement construction. The HL7 language took its meaning from the HL7 Reference Information Model (30). It described how the information should be combined into meaningful units. Two templates for the HL7 Clinical Document Architecture were used in this research: the Chronic Kidney Disease Discharge Summary and the Care Record Summary. Both templates used the HL7 Clinical Statement Model for structured data. This included lab results, medication events, vital signs, diagnoses and procedures.

The HL7 Template for Chronic Kidney Disease Discharge Summary was designed to prompt for patient data needed for chronic disease management. The discharge summary study results were compared to the data elements considered relevant in the Canadian Chronic Disease Management Model balloted by the international HL7 community in June 2006[10] (200).

IV.A.3 Semantic Structure

It was hypothesized that semantic interoperability among electronic health resources could be achieved using a range of UMLS source vocabularies that provide domain coverage. Our knowledge determines the way we organized concepts. The UMLS maintains a vast amount of source data and the UMLS Knowledge Sources—Metathesaurus, Semantic Network and

[9] http://www.dhmc.org/qualityreports/list.cfm?metrics=DM
[10] http://www.whic.org/public/profiles/CDMStandardsDocuments.html

Specialist Lexicon—construct meaning from the way concepts are organized and represented ontologically (189).

The clinical pragmatic patterns were expressed using the HL7 Clinical Statement Model and a constrained term lexicon. The term lexicon was coded to one or more of the seven terminology system boundary objects: ICD-9, ICD-9-CM, ICD-10-CA, SNOMED CT, SNOMED 3.5, HL7 Version 3 and UMLS. UMLS included mappings between the ICD-9-CM and SNOMED CT code sets. The mapping was provided by SNOMED International Organization. Other mappings in UMLS were through thesauri relationships to ICD-10, SNOMED 3.5 and HL7.

The classification of entities in reality is considered "a vital contribution to ensuring the interoperability of coding systems and healthcare records in the future" (198). There was an overlap at the interface between different information, technology and inference models, so there were consequences for each set of choices (195). These consequences helped describe the determinants of boundary object components chosen for the boundary infostructure.

IV.A.4 User Contexts

The usefulness was evaluated from the perspective of reuse. This included facilitating migration of data to the Western Health Information Collaborative Chronic Disease Management data standard (5); rendering patient data for the longitudinal record based on the HL7 Care Record Summary template (200); and rendering patient data for the Canadian Organ Replacement Register Initial Registration Form[11].

The HL7 Template for Care Record Summary was designed to capture the longitudinal record for a patient. It was evaluated as a tool for transforming content from the electronic discharge summary into encounter entries for a patient's longitudinal electronic health record.

IV.A.5 Terminology And Effective Communication

The terminology used in the Transcription versus Templates study was analyzed to produce a defined set of subjects. The process included the following steps.

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[11] http://healthinfo.med.dal.ca/dme/RenalClinicUseCases.pdf

1. Construct text corpora from items in the patient chart and discharge summary examples. Appendix A lists the items in the chronic kidney disease text corpus
2. Identify clinical concepts in text using terminological extraction methods.
   a. MetaMap Transfer (MMTx)[12]. This software takes an input sentence, separates it into phrases, identifies the medical concepts and assigns proper semantic categories to them according to the knowledge embedded in UMLS (201). MMTx software version 2.4.B was used for the automatic indexing of the text corpus. Text was first processed in an unrestricted mode and then constrained to UMLS concepts arising from SNOMED CT or SNOMED-based (SNOMED 3.5 and SNOMED CT) source vocabularies. Each term was mapped to a concept unique identifier (CUI). Where there were multiple candidate CUIs generated when mapping text to an UMLS code, the UMLS semantic class was used to filter the CUI(s) for appropriateness.
   b. Manual indexing. Human indexers, familiar with the medical terminology, assigned UMLS concept identifiers (CUI) to index terms in the text corpora. The UMLS Rich Release Format Browser version 2005AC was used for word search, tree browser and CUI search.
3. Constrain terminology to a fixed list of the terms used in the text corpora that are uniquely identified by their mapping to a UMLS CUI.

The constrained terminology provided a defined set of subjects for evaluation of the effective communication qualities of the discharge summaries. The purpose was to determine if we were able to improve the pragmatic proficiency of those authoring the discharge summary.

Grice laid out a set of rules for the Cooperative Principle (24) for effective communication. The Gricean maxims formed the framework for evaluating the attributes of the discharge summaries produced with and without the benefit of the HL7 Template for Chronic Kidney Disease Discharge Summary. The maxim of quantity states that you should say only what is needed and be sufficiently informative but not more informative than is required. The maxim of quality states that you should not say what you believe to be false and not say that for which

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[12] http://mmtx.nlm.nih.gov

you lack adequate evidence. The maxim of relevance states that you should say only what is pertinent to the context of the conversation at the moment. The maxim of manner states that you should avoid obscurity of expression, avoid ambiguity, be brief and be orderly.

IV.A.6 Semantic Interoperability Between HL7 CDA And Subject Descriptions

The competencies that are pertinent to the development of pragmatic proficiency in the production of clinical documents used for communication and learning include interpreting available data and integrating information to generate differential diagnoses and follow-up plans (147). For pragmatic interoperability, the recipient of the communication must understand the information so they can act on it. This research linked concept descriptions and online drug profiles to the clinical documentation and evaluated its usability from the author's perspective.

1. Generate concept descriptions from CLUE Browser[13] for SNOMED CT for all terms directly codable to SNOMED CT and store on web server with unique URLs
2. Enter the unique URLs for diagnoses and lab tests from 4 above into the clinical statement patterns for HL7 CDA entries for diagnoses and lab tests
3. Enter the unique URLs for drug descriptions from the online Nova Scotia Formulary into the clinical statement patterns for HL7 CDA entries for medication events
4. Render the HL7 CDA documents created through use of the HL7 Template for Chronic Kidney Disease (CKD) Discharge Summary as web pages with links to the published subject indicators (PSI) from 5 and 6 above

IV.A.7 HL7 Template For The CKD Discharge Summary

The HL7 Template for CKD Discharge Summary was implemented on a web server for the data entry task. Guidance for this task was provided by the study's *Chronic Kidney Disease Discharge Summary User Manual.* Figures IV.6 through IV.12 were taken from this user manual.

HealthInfoRx™ was a private, secure and confidential website for patients and health professionals. The recruited participants were consented. They entered the CKD Clinic (a

[13] http://www.clininfo.co.uk/clue5/clue.htm

virtual clinic) by clicking on the link (Figure IV.2). They were then prompted to enter their username and password.

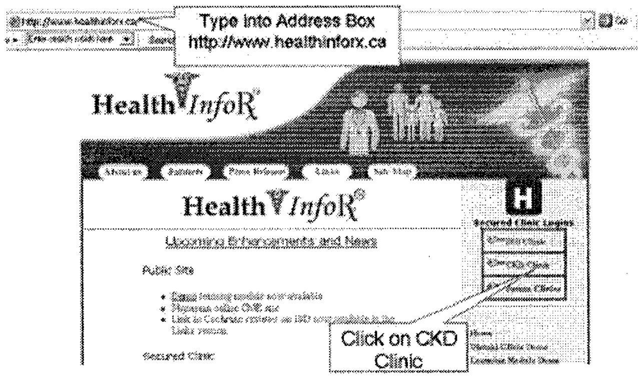
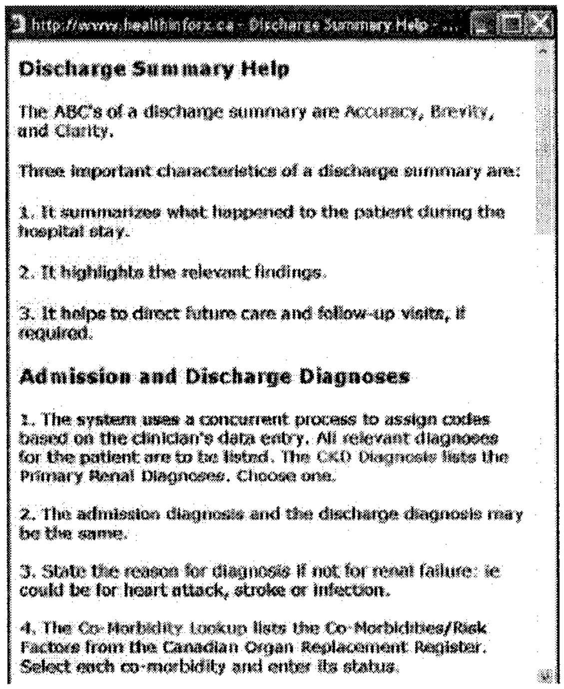


Figure IV.2 Opening Screen for CKD Template for Discharge Summary

The *Discharge Summary Training Manual: Purposes and Specifics of Discharge Summaries* was prepared in a print format by the Education Office, Department of Medicine, Dalhousie University and QEII Health Sciences Centre. The manual was adapted for creation of an electronic discharge summary via the HL7 Template for CKD Discharge Summary and available online (Figure IV.3).



http://www.healthinforx.ca - Discharge Summary Help - ...

Discharge Summary Help

The ABC's of a discharge summary are Accuracy, Brevity, and Clarity.

Three important characteristics of a discharge summary are:

1. It summarizes what happened to the patient during the hospital stay.

2. It highlights the relevant findings.

3. It helps to direct future care and follow-up visits, if required.

Admission and Discharge Diagnoses

1. The system uses a concurrent process to assign codes based on the clinician's data entry. All relevant diagnoses for the patient are to be listed. The CKD Diagnosis lists the Primary Renal Diagnoses. Choose one.

2. The admission diagnosis and the discharge diagnosis may be the same.

3. State the reason for diagnosis if not for renal failure: ie could be for heart attack, stroke or infection.

4. The Co-Morbidity Lookup lists the Co-Morbidities/Risk Factors from the Canadian Organ Replacement Register. Select each co-morbidity and enter its status.

Figure IV.3 Online Version Of Discharge Summary Training Manual

When the user clicked on the *CKD Diagnosis* button (Figure IV.4), he was shown the same list of diagnoses as used by clinical staff for scheduling outpatient visits in the Chronic Kidney Disease Clinic and for completing the Primary Renal Diagnosis field in the patient registration form, Canadian Organ Replacement Register.

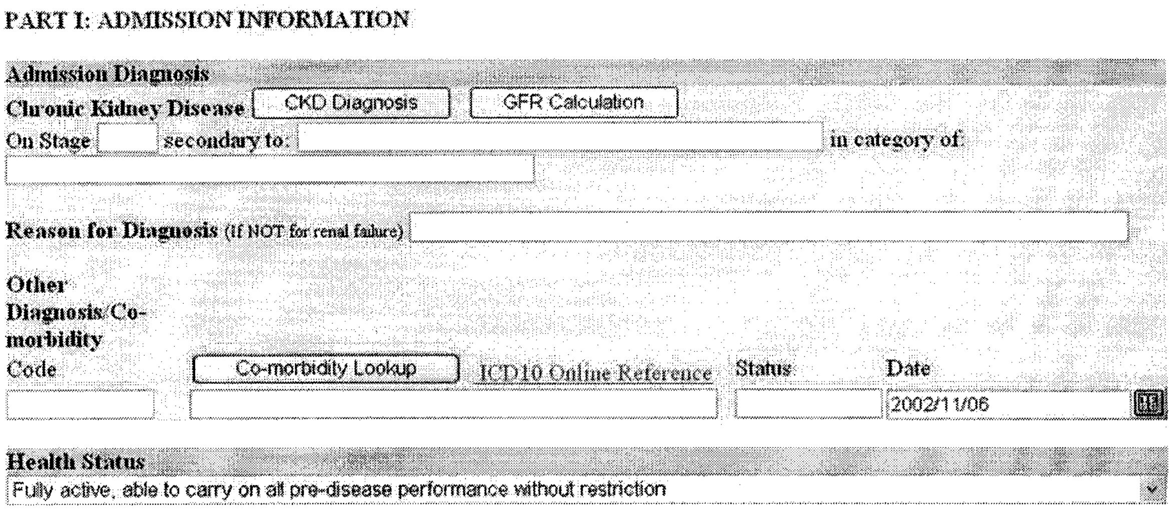
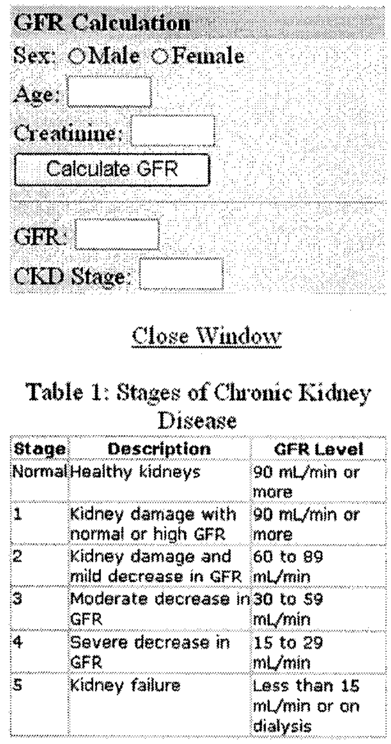


Figure IV.4 Screenshot Of The Admission Diagnosis Section

The *On Stage* field in Figure IV.4 was automatically populated based on the glomerular filtration rate (GFR) result (Figure IV.5) that arose from use of the onscreen *GFR Calculation* calculator. The ICD10 *Code* and description were automatically filled in when the user selected a co-morbidity from the *Co-morbidity Lookup*. The user was able to link to the World Health Organization's online ICD10 database[14] for contextual information or for selecting a co-morbidity not found in the lookup list. The *status* field was needed for information reuse. The available options were 'yes', 'no' and 'unknown'.

[14] http://www.who.int/classifications/apps/icd/icd10online/



Stage	Description	GFR Level
Normal	Healthy kidneys	90 mL/min or more
1	Kidney damage with normal or high GFR	90 mL/min or more
2	Kidney damage and mild decrease in GFR	60 to 89 mL/min
3	Moderate decrease in GFR	30 to 59 mL/min
4	Severe decrease in GFR	15 to 29 mL/min
5	Kidney failure	Less than 15 mL/min or on dialysis

Figure IV.5 Glomerular Filtration Rate Calculator For CKD Stage

There were three sections in the CKD Template: Admissions Summary (Figure IV.6), Course in Hospital and Discharge Summary.

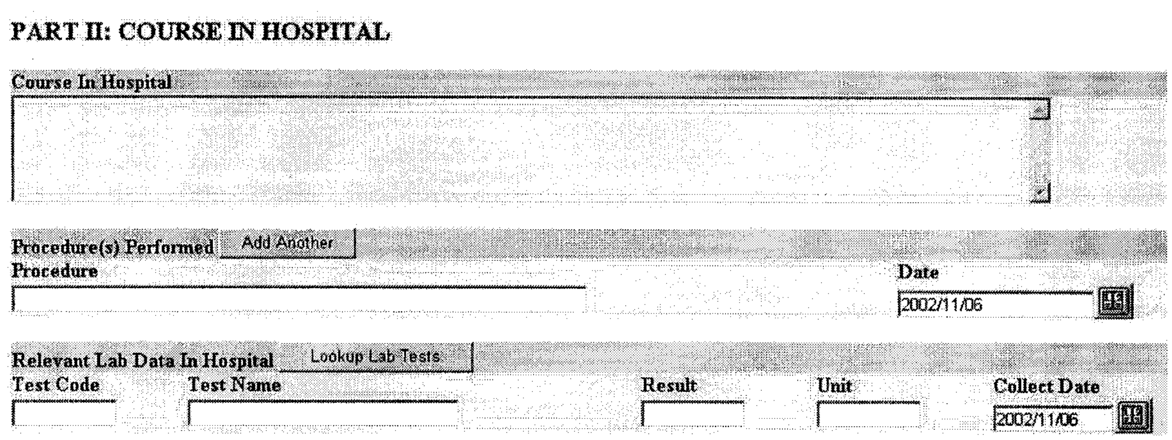
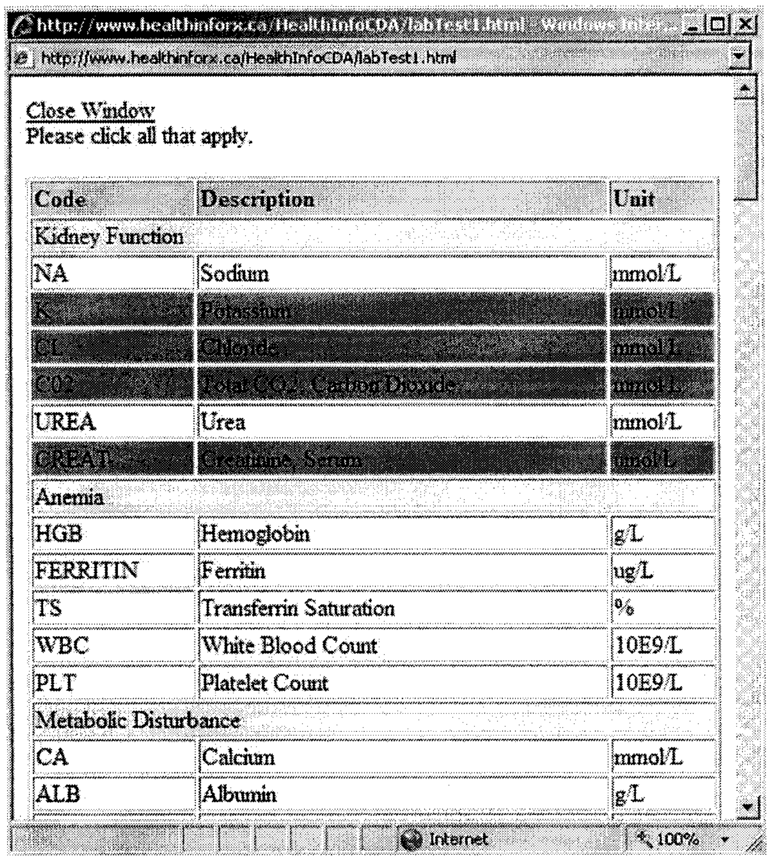


Figure IV.6 Screenshot Of The Course In Hospital Section

The summary of the diagnoses made and the treatments instituted were entered as free text into the *Course in Hospital* and *Procedure(s) Performed* fields. *Test Code, Test Name* and *Unit* fields in the *Lab Data* section were automatically populated when the user clicked on entries in the *Lab Lookup* screen (Figure IV.7). The same *Lab Lookup* screen was used for collecting lab results in the Admission, Course in Hospital and Discharge sections of the HL7 Template.



Code	Description	Unit
Kidney Function		
NA	Sodium	mmol/L
K	Potassium	mmol/L
CL	Chloride	mmol/L
CO2	Total CO2, Carbon Dioxide	mmol/L
UREA	Urea	mmol/L
CREAT	Creatinine, Serum	umol/L
Anemia		
HGB	Hemoglobin	g/L
FERRITIN	Ferritin	ug/L
TS	Transferrin Saturation	%
WBC	White Blood Count	10E9/L
PLT	Platelet Count	10E9/L
Metabolic Disturbance		
CA	Calcium	mmol/L
ALB	Albumin	g/L

Figure IV.7 Screenshot From Lab Lookup For CKD Template

The *Medications* field (Figure IV.8) were populated by keying in the medication or by using "cut and paste" from the information available in the Nova Scotia Drug Formulary[15]. Over the counter medicines, such as aspirin[16], were excluded for reimbursement under the Pharmacare program, so were not listed in the formulary. The study participant was asked to enter the reason for a medication. The terminological knowledge available from the formulary drug details was a source for this information. Each drug formulary entry listed the therapeutic main group, therapeutic subgroup, chemical/therapeutic subgroup and subgroup of chemical

[15] http:/www.gov.ns.ca/health/pharmacare/formulary.asp
[16] http://www.gov.ns.ca/heal/pharmacare/benefits_faq.htm

substance. The information was based on the World Health Organization Anatomical Therapeutic Chemical (ATC) Classification[17].

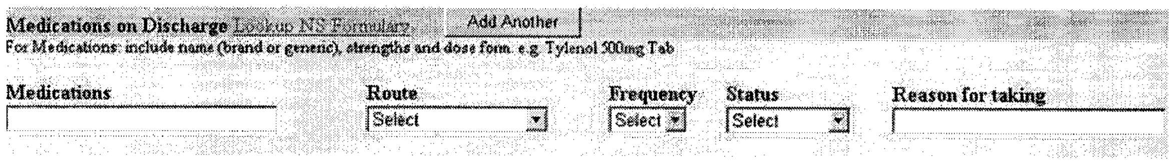
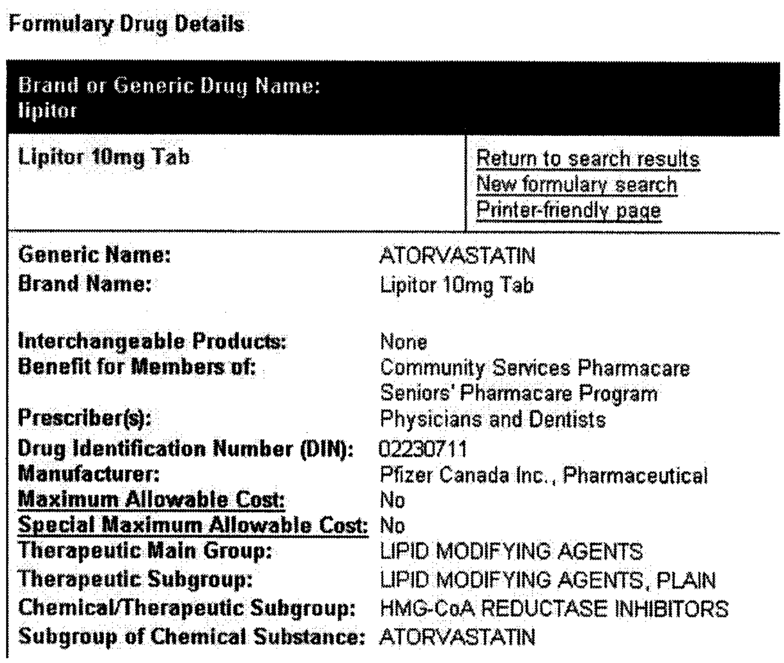


Figure IV.8 Screenshot From Medications On Discharge Section Of CKD Template

Medications had both a generic and a brand name, and some medications were classified multiple ways. One discharge medication was classified as both an antihypertensive and an urological. This finding indicated that the online lookup at the time of data entry might introduce cognitive confusion but that this would be mediated by knowledge and experience. Figure IV.9 is a screen shot for a formulary entry[18].



Formulary Drug Details

Brand or Generic Drug Name:
lipitor

Lipitor 10mg Tab

Return to search results
New formulary search
Printer-friendly page

Generic Name:	ATORVASTATIN
Brand Name:	Lipitor 10mg Tab
Interchangeable Products:	None
Benefit for Members of:	Community Services Pharmacare Seniors' Pharmacare Program
Prescriber(s):	Physicians and Dentists
Drug Identification Number (DIN):	02230711
Manufacturer:	Pfizer Canada Inc., Pharmaceutical
Maximum Allowable Cost:	No
Special Maximum Allowable Cost:	No
Therapeutic Main Group:	LIPID MODIFYING AGENTS
Therapeutic Subgroup:	LIPID MODIFYING AGENTS, PLAIN
Chemical/Therapeutic Subgroup:	HMG-CoA REDUCTASE INHIBITORS
Subgroup of Chemical Substance:	ATORVASTATIN

Figure IV.9 Drug Formulary Terminology Knowledge

[17] http://www.gov.ns.ca/health/pharmacare/acdr_brochure.htm
[18] http://www.gov.ns.ca/health/pharmacare/

Narrative text data entry was supported for sections titled "History of Present Illness"; "Relevant Past Medical and Surgical History"; "Allergies and Adverse Reactions"; "Social"; "Family History"; "Immunization"; "Physical Examination-Others"; "Course in Hospital"; "Procedure"; "Reason for Taking Medication"; "Dialysis Order"; and "Follow-up Plans".

The user clicked on the *Save as CDA XML* button at the foot of the CKD Template to save his discharge summary in the web server. He was then directed to a page where he could view his discharge summary. It appeared in a form similar to the one shown in Figure IV.10.

Admission Date: 2002-Nov-06 Discharge Date: 2002-Nov-12

Admission Diagnosis

Stage 5 Chronic Kidney Disease [GFR = 9 mL/min/1.73m^2, Creatinine = 553 umol/L]

CKD Diagnosis: Chronic renal failure - etiology uncertain [000]

Reason for Diagnosis:

Code	Diagnosis/Co-morbidity	Status	Date
E11	Non-insulin-dependent diabetes mellitus (Type 2)	Unknown	2002-Nov-06
I10	Essential (primary) hypertension	Unknown	2002-Nov-06
M10	Gout	Unknown	2002-Nov-06
Z87.8	Other - Hypercholesterolemia	Unknown	2002-Nov-06

Health Status: Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature.

Discharge Diagnosis

Stage 5 Chronic Kidney Disease [GFR = 9 mL/min/1.73m^2 , Creatinine = 553 umol/L]

CKD Diagnosis: Hypertensive nephrosclerosis [072]

Reason for Diagnosis:

Code	Diagnosis/Co-morbidity	Status	Date
			2002-Nov-12

A D M I S S I O N S U M M A R Y

History of Present Illness

Not aware of any renal problems until started on ibuprofen for gout February 2002 and on an increasing dose of Avalide between February and March 2002. At this time, serum creatinine noted to increase. No complaints of uremic symptoms- no reported nausea, vomiting, leg swelling, itchiness, decrease urine output, hematuria, dysuria, SOB, orthopnea, PND, chest pain, cough/sputum, change in bowel habit, skin rash, or arthralgia. Occasional complaints of left foot pain.

Relevant Past Medical and Surgical History

Diabetes Mellitus x ~ 10 years Hypertension x ~ 20 years Gout Hypercholesterolemia Previous Tonsillectomy

Allergies and Adverse Reactions

Cause	Note

Social History

Non-Smoker No Alcohol Use

Family History

Disease	Subject	Description
Diabetes	mother, brother	Not known

Figure IV.10 Discharge Summary Completed From HL7 Template

There was a web page for each diagnosis in the Primary Renal Diagnosis lookup (N=101), co-morbidity lookup (N=21) and lab result lookup (N=116). Figure IV.11 shows a screen shot of *potassium disorder,* SNOMED CT code 24529006, with its distributed relationships and Figure IV.12 with its hierarchy (parent term, *"disorder of electrolytes",* and child terms, *disturbance of potassium balance of newborn, hyperkalemia, and hypokalemia).* A child term, *hyperkalemia*, appeared elsewhere in the infostructure, in the triage for Nephrology [19].

[19] http://dom.medicine.dal.ca/waitlists/CHWaitTimesSept06.pdf

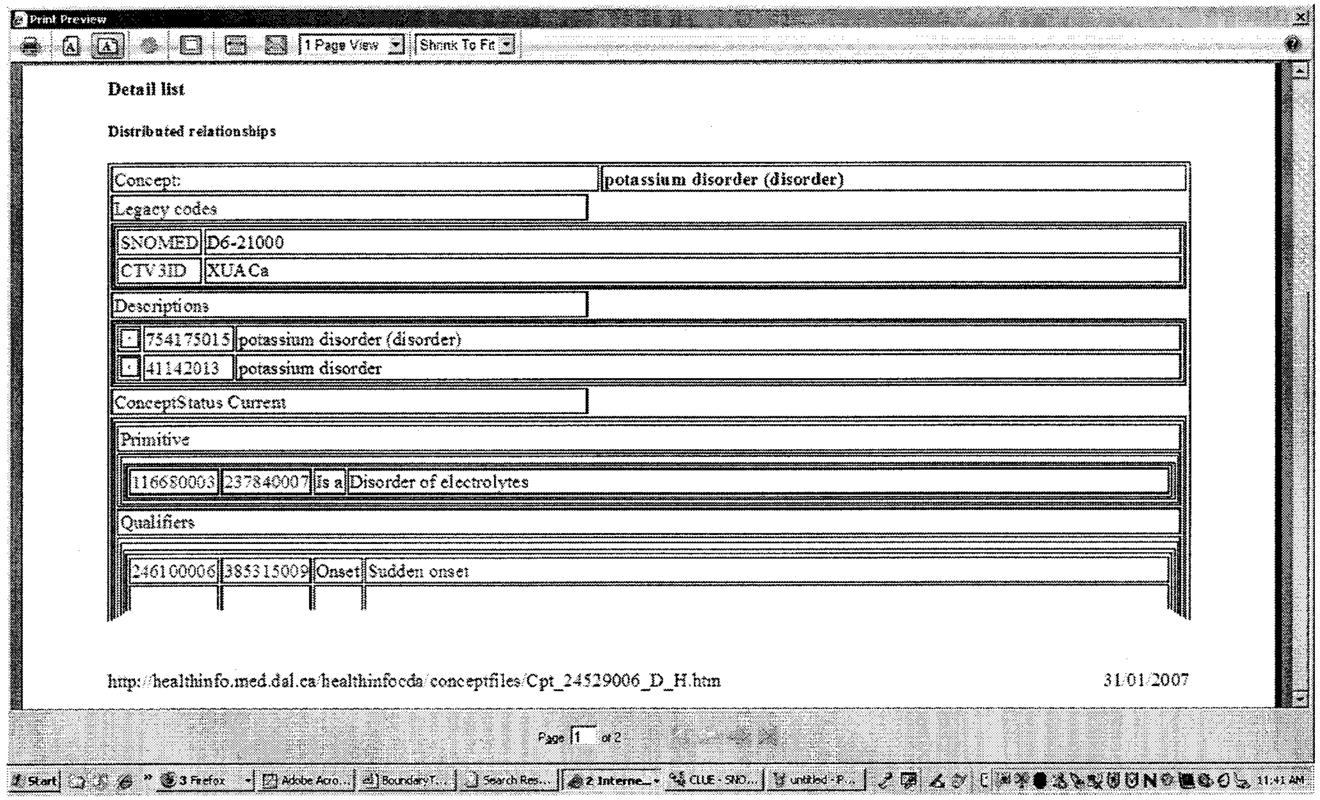


Figure IV.11 SNOMED CT Concept Description Distributed Relationships

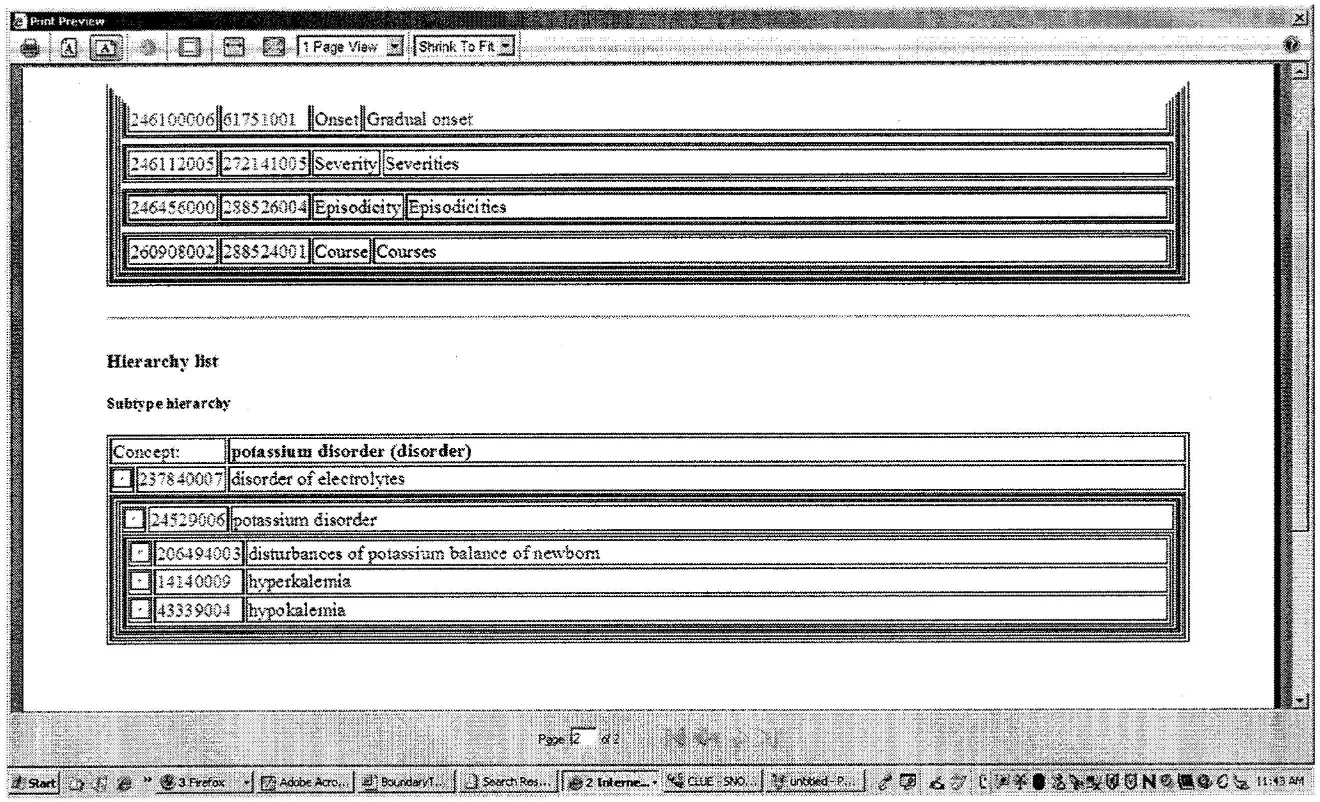


Figure IV.12 SNOMED CT Concept Description Hierarchy List

Medication entries in the HL7 CDA were linked to the Nova Scotia Drug Formulary (Figure IV.9) if the medication had previously been identified for the constrained terminology.

Co-morbidity diagnosis entries were linked to the International Statistical Classification of Diseases and Related Health Problems 10th Revision (ICD-10) online database[20]. The participant was also given the opportunity to view the coded information for the encounter that was sent to the Canadian Institute for Health Information. Diagnosis information was coded using ICD-10-CA, a Canadian modification of ICD-10, and procedure information was coded using CCI (Canadian Classification for Health Interventions).

IV.A.8 Constrained Terminology

The data used in information exchange among clinicians was termed language data. It is largely nonnumeric in nature and formulated almost exclusively within the constructs of natural language. "Language data are the word, phrase, or sentence tokens acceptable (understood) within the domain of a natural language." (156, p. 102).

The residents' usage of terms in the dictated discharge summary and narrative portions of the template-based discharge summary was an experiential lexicon. The residents had access to the patients' paper chart, so all terms in the chart also formed part of the experiential lexicon. The terms available for concurrent coding in the template were an imposed lexicon. The lexicon was constructed from both experiential and imposed sources.

The CDA document had a structured body which was populated from data entered into the sections of the CKD Template. The starting lexicon was the list of all the terms used in the production of a discharge summary. Both HL7 Vocabulary and SNOMED CT are source vocabularies in the Unified Medical Language System (UMLS). Each term in the lexicon was associated with its UMLS Concept Unique Identifier (CUI). The final lexicon was all terms in the starting lexicon (N=272 concepts) plus additional terms used by the residents in narrative text entries (N=605 concepts). Multiple terms could be associated with the same UMLS CUI, because a concept may have synonyms and lexical variations. The constrained terminology was

[20] http://www.who.int/classifications/apps/icd/icd10online/

formed from a bounded set of 877 UMLS CUIs. Table IV.1 displays a partial lexicon by HL7 CDA document section with the source vocabulary in UMLS, where applicable.

Table IV.1 Lexicon From The CKD Template

Document Section	Lexical Terms	Terminology/Value Set
Hospital Admission Dx	Stage, GFR, CKD Diagnosis (101 terms), Co-Morbidity (21 terms)	SNOMED CT, ICD-10, HL7 Vocabulary Domain (ObservationInterpretation) for stage
Admission Health Status	Fully active …, restricted …, ambulatory …, limited self-care …, completely disabled …, dead (5 terms)	HL7 Vocabulary Domain (ObservationInterpretation) for Eastern Cooperative Oncology Group (ECOG) values
Hospital Discharge Dx	Stage, GFR, CKD Diagnosis (101 terms), Co-Morbidity (21 terms)	SNOMED CT, ICD-10, HL7 Vocabulary Domain (ObservationInterpretation) for stage
History of Present Illness	Free text	
Relevant Past Medical and Surgical History	Free text	
History of Allergies	Free text	
Social History	Free text	
History of Family Member Diseases	Hypertension, diabetes, kidney disease, cardiac disease, hepatitis	SNOMED CT
History of Immunization	Free text	
Vital Signs	Blood Pressure-Systolic; Blood Pressure-Diastolic; Height; Weight; Heart Rate; Respiratory; temperature	SNOMED CT
Relevant Lab Data on Admission	Lookup List. 116 mnemonics from the Cerner PathNET Lab System with description; e.g., 'TS' is the mnemonic used for 'Transferrin Saturation'	SNOMED 3.5
Relevant Lab Data in Hospital	Lookup List (116 terms)	SNOMED 3.5
Hospital Discharge Medications	Lookup in Drug Formulary; Route; Frequency	SNOMED CT; HL7 vocabulary
Hospital Course	Free text	
Procedures	Free text	
Discharge Health Status	Fully active …, restricted …, ambulatory …, limited self-care …, completely disabled …, dead (5 terms)	HL7 Vocabulary Domain (ObservationInterpretation) for Eastern Cooperative Oncology Group (ECOG) values
Relevant Lab Data on Discharge	Lookup List (116 terms)	SNOMED 3.5
Dialysis Order	Free text	

Document Section	Lexical Terms	Terminology/Value Set
Hospital Discharge Followup	Free text	

The discharge summary is considered in light of its status as a partial map of the documentation in the patient chart. Discharge summaries are created by study participants using a common referent, the patient chart for a specific Hospital Unit Number. Paper charts are organized using the Universal Chart Order (Table IV.2). This means the chart is kept in the same order on the clinical floor and in the medical records department. All forms are filed according to their source, such as laboratory or pharmacy.

Table IV.2 Chart Order

Folder Section	Document
ADMISSION AND DISCHARGE	Inpatient Admission Form Antibiotic Resistant Organism Admission Screening Record
PHYSICIANS ORDERS	Physician's Orders (handwritten) Drug Interaction Warnings
HISTORY AND PHYSICAL	Progress Notes (handwritten) Clinic Letter
PROGRESS RECORDS	Progress Notes (handwritten) Discharge Medication Forms (handwritten)
CONSULTATIONS	Nutrition Screen and Consult
OPERATION RECORD	Surgical Pathology Report
NURSING RECORDS	Patient Admission Assessment (handwritten) Nursing Basic Care Flow Record (handwritten)
GRAPHIC RECORDS	Vital Signs (handwritten) Nursing Glucose Record (handwritten) 24 Hr Intake & Output (handwritten)
DIAGNOSTIC REPORTS	Diagnostic Imaging Report
LAB REPORTS	Clinical Chemistry Lipids Urinalysis Urine Volume Tests Endocrinology General Hematology Routine Coagulation Special Hematology Immunopathology Immunology Blood Transfusion Service Report Microbiology Cancelled Tests
MEDICATION RECORDS	Medication Record/7 Day (handwritten)
MISCELLANEOUS	Diagnostic Imaging Consent Form

IV.A.9 Gricean Analysis Of Discharge Summaries

Each study participant produced two different artifacts, the transcription-based discharge summary and the template-based discharge summary. This provided paired samples (3 transcription-based and 3 template-based).

The results from beta testers for the template-based discharge summary (N=3) were analyzed for content. This decision was made because beta-testers included nurses and nephrologists.

To get human-readable formats, the system processed the template and queried for the data stored in database tables at the time of data entry. The data had been coded concurrent with data entry, so clinicians could view their electronic discharge summary using Internet Explorer (Figure IV.10) and link from coded fields to concept descriptions. This increased pragmatic information content.

No feedback was given to the participant for his dictated discharge summary. This task required secretarial resources for transcription into a word-processed document. The content was analyzed for subjects. A CDA Header was produced with a *summary* section listing all subjects in the document and the word processed document was included as a linked object in the CDA non XML body. The instance was stored in the CDA Repository. In this way, the CDA Repository was populated with semantic indexing of documents through the summary section.

A discharge summary composed by the physician or nurse was scored by section and overall for correctness, completeness, clarity, conciseness, brevity and term relevance. Grice's quantity maxim was to "say only what is needed", and his relevance maxim was to "say only what is pertinent to the context of the conversation at the moment" (26). Each discharge summary was assessed for its quantity and relevance maxims by an independent evaluator. Each section was scored for completeness, conciseness and brevity. Table IV.3 lists scores for discharge summaries that were dictated and transcribed. The Likert scale was 1 for Inappropriate/Low to 5 for Appropriate/High.

Table IV.3 Scores For Discharge Summaries Created By Dictation And Transcription

	11111 BetaTest	22222 BetaTest	33333 BetaTest	24140 Paired	58797 Paired	88065 Paired
Admitting Diagnosis	5	4	3	5	4	5
Discharge Diagnosis	4	3	2	2	4	3
LAB DATA						
Completeness	4	4	3	4	4	4
Brevity	3	4	2	4	3	3
Discharge Recommendations	2	5	2	2	4	5
HISTORY						
Completeness	4	3	3	3	4	4
Conciseness	3	4	2	4	3	3
Brevity	3	4	2	4	3	3
PHYSICAL						
Completeness	4	1	3	4	3	3
Conciseness	4	1	2	4	3	4
Brevity	4	1	2	4	3	4
HOSPITAL COURSE						
Completeness	4	3	3	4	3	4
Conciseness	4	3	2	4	2	3
Brevity	4	4	2	4	2	3
OVERALL IMPRESSION						
Length	4	4	2	4	3	4
Structure	4	3	2	3	3	4
Language	4	4	2	4	3	4
Global Rating	4	4	2	4	3	4
TOTAL	68	59	41	67	57	67

Table IV.4 lists scores for discharge summaries that were data entered by Template.

Table IV.4 Scores For Discharge Summaries Data Entered By Template

	24140	58797	88065
Admitting Diagnosis	5	5	5
Discharge Diagnosis	4	4	5
LAB DATA			
Completeness	4	5	5
Brevity	3	3	4
Discharge Recommendations	3	4	5

	24140	58797	88065
HISTORY Completeness Conciseness Brevity	4 4 3	5 3 3	5 4 4
PHYSICAL Completeness Conciseness Brevity	3 3 3	5 4 4	1 1 1
HOSPITAL COURSE Completeness Conciseness Brevity	 4 3 3	 5 4 4	 5 5 5
OVERALL IMPRESSION Length Structure Language Global Rating	 3 4 4 4	 4 5 4 4	 4 5 4 4
TOTAL	64	75	72

Three of the discharge summaries were from beta-testers, so were not used in the calculation. For the paired subjects, the mean score for the controls (transcribed discharge summaries) was 63.7 and for the experiment (data entry using a discharge summary template) was 70.3. Due to sample size limitation, the scores were not statistically significant. However, they implied that the discharge summary produced using the template would score higher than the discharge summary produced, by the same resident, using the transcription method.

Grice's quality maxim was to "say only that for which there is evidence" (26). The evidence was what was documented in the patient chart and the clinician's interpretation of the documentation based on his knowledge. The referent tracking for the subjects formed the framework for evaluating how well the boundary infostructure supported the CKD Discharge Summary as a communications channel.

There were 84 subjects that were considered for referent tracking in the 72-page patient chart. Appendix D gives the list of subjects with their associated chart pages. Referent tracking is accomplished by associating a subject with how it is used in the patient chart context. For example, subject *108537001* is about *amlodipine*, a generic name for *Norvasc,* a medication the patient was taking on admission. The subject has five referents in the patient chart. Each page of the chart was scanned and put into an HL7 CDA XML document so it could serve as an eHealth resource.

Table IV.5 lists the content scores for each discharge summary produced. There were 84 subjects for which content was sought.

Table IV.5 Quality Maxim Scores For Each Participant's Discharge Summary

Participant	**Type of Summary**	**Quality Score (out of 84)**
24140	Template	58
24140	Transcription	47
58797	Template	74
58797	Transcription	66
88065	Template	59
88065	Transcription	56
35197	Template – Beta test	46
74140	Template – Beta test	47
75281	Template – Beta test	66
97852	Template – Beta test	62
11111	Transcription – Beta test	45
22222	Transcription – Beta test	35
33333	Transcription – Beta test	52

The trend for the mean quality score of the Template (63.67) and Template-Beta test (63.25) was to show improvement over the mean quality score of the Transcription (56.33) and Transcription-Beta test (44.0). However, due to the small sample size these statistics were not significant.

Grice's manner maxim instructed us to "avoid obscurity of expression", "avoid ambiguity", "be brief" and "be orderly" (26). This maxim was evaluated from the perspective of the user's assessment of the HL7 Template for a CKD Discharge Summary. Feedback was sought from a medical clerk (year 3 and 4 of medical school), a resident and a physician-trained health informatician (Table IV.6).

Table IV.6 Feedback Questionnaire Results

Statements	Clerk	Resident	MD/Health Informatician
I was able to enter all the important data elements	Agree	Agree	Neutral
I found the diagnosis terms I needed in the Lookup List	Agree	Strongly Agree	Disagree
I found the laboratory terms I needed in the Lookup List	Agree	Agree	Agree
I found the medications I needed via link to the Nova Scotia Drug Formulary	Disagree	Agree	Agree
I found that structuring content into Admission, Course in Hospital, and Discharge sections was relevant to me	Agree	Strongly Agree	Strongly Agree
I am comfortable using a computer for data entry of discharge summaries	Agree	Strongly Agree	Strongly Agree
I found the Electronic Discharge Summary easy to use	Neutral	Agree	Agree
I was able to enter all the important data elements	Agree	Agree	
I dictated in a way that makes it easy for transcriptionists to transcribe the dictation	Agree	Neutral	
I was sufficiently informative for the purpose of a discharge summary	Neutral	Agree	
I am comfortable using dictation for data entry of discharge summaries	Neutral	Agree	Agree
I found the Transcription System easy to use	Agree	Neutral	
Colour choices were appropriate	Agree	Neutral	Agree
Layout was logical	Agree	Agree	Agree
Text was large enough	Agree	Disagree	Agree
Information was expressed as expected	Agree	Disagree	Neutral
Amount of content was appropriate	Agree	Agree	Neutral
Did you access the terminological knowledge available via links from the codes in your electronic discharge summary?	Yes	Yes	Yes
If yes, did it enhance your understanding of the terminology used	Yes	Yes	Yes
Did you access the CIHI discharge abstract for this patient encounter that was provided as feedback?	Yes	Yes	Yes
If yes, was this feedback helpful in understanding how the information you enter is coded for reimbursement and epidemiology purposes	Yes	Yes	Yes
Did you seek information in the Chronic Kidney Disease HL7 Templates User Guide?	Yes	No	Yes
If yes, was it helpful	Yes		Yes
Did you seek information in the Discharge Summary Training Manual via help icon in the online form?	Yes	No	Yes
If yes, was it helpful	Yes		Yes

IV.B Study One Phase Two

A formative evaluation assessed the boundary infostructure solution against its stated objectives. The created boundary objects in the infostructure were:

1. HL7 Template for Chronic Kidney Disease Discharge Summary

2. Semantic Index for HL7 CDA

3. Clinical Document Repository

4. Chronic Kidney Disease Topic Map

The findings from the Transcription versus Templates research were used in boundary object creation. The five objectives were:

1. Practical data entry: to produce an electronic discharge summary using data entry by clinicians and to address issues expressed in their feedback
2. Pragmatic proficiency: to prompt authors for the essential data elements for a more complete discharge summary
3. Pragmatics of terminology implemented in software: to transform content in a patient chart into HL7 CDA documents
4. Indexing: to normalize content from two heterogeneous sources (patient chart, discharge summaries) by indexing the contents
5. Retrieval and reuse: to generate forms based on normalization of structured data from the electronic discharge summary for administrators, medical educators and patients

IV.B.1 Practical Data Entry And Feedback

The boundary infostructure supported the task of producing a discharge summary using direct data entry. The data entry was practical because it supported concurrent coding of content and provided the user with links to online resources (Nova Scotia Drug Formulary and World Health Organization ICD-10 Online Database) that facilitated "just in time" learning. Through links from codes to concept descriptions, it taught clinical concepts by means of examples and by practice.

IV.B.2 Pragmatic Proficiency

Each clinician had a different style of reporting and of using medical language. However, the markers for disease progression were commonly agreed upon by medical educators, researchers and clinicians. WHIC-CDM data standard identified a cluster of observations that result from laboratory or other diagnostic exam results (5). The percentage of data elements entered by our study beta-testers and subjects (N=7) is given in Table IV.7.

Table IV.7 WHIC-CDM Markers Of Disease Progression Entered Into Template

WHIC-CDM Markers of Disease Progression	Study Results	SNOMED CT	Top Level
A1C	71%	365845005	finding
Total Cholesterol	57%	301860006	substance
HDL Cholesterol	71%	102737005	substance
LDL Cholesterol	71%	102739008	substance
TC HDL Cholesterol ratio	71%	166842003	procedure
Triglycerides	71%	85600001	substance
Serum Creatinine	100%	15373003	finding
Creatinine clearance – calculator provided in chronic kidney disease template (GFR)	100%	80274001	observable entity
24 hour urinary protein	100%	50456001	substance
Serum Potassium	100%	365760004	finding
Serum Sodium	100%	365761000	finding
Hemoglobin	100%	38082009	substance
Transferrin Saturation	100%	165730006	procedure
Serum Calcium	86%	5540006	substance
Serum Phosphorus	86%	30820000	substance
Serum Albumin	86%	52454007	substance
Alanine aminotransferase (ALT)	71%	56935002	substance
Creatine Kinase (CK)	71%	75828004	substance

Despite the variation in the volume of lab data that was recorded, there was a common set of 13 lab results reported by all beta-test and study participants (N=7). Table IV.8 reports these with their SNOMED codes, version 3.5 and CT, and SNOMED CT hierarchy.

Table IV.8 Common Set Of 13 Lab Test Results With SNOMED Codes

Test Name	SNOMED 3.5	SNOMED CT	Top-Level	Is-a Hierarchy
Potassium	F-0191E	365760004	Finding	Electrolyte levels-finding
Sodium	F-0191F	365761000	Finding	Electrolyte levels-finding
Chloride	F-01920	365762007	Finding	Electrolyte levels-finding
Test Name	**SNOMED 3.5**	**SNOMED CT**	**Top-Level**	**Is-a Hierarchy**
Creatinine, serum	F-61390	15373003	Finding	Nitrogenous waste product
Urea	F-61C86	387092000	Substance	Simple physiological organic compound
URR Protein (24 Hours)	F-73000	50456001	Substance	Protein
Anti-DNA	F-C2600	6741004	Substance	Antinuclear antibody
C4 Complement, Serum	F-C7053	300899005	Substance	Complement component classic pathway
C3 Complement, Serum	F-C7150	10473000	Substance	Complement component classic pathway
Hemoglobin	F-D5000	38082009	Substance	Binding protein
ENA Screen	P3-60217	412877001	Procedure	Immunology screening test
Total CO2	P3-73015	391396001	Procedure	Blood bicarbonate measurement
Transferrin Saturation	R-F3BD5	165730006	Procedure	Total iron binding capacity measurement

The structured and unstructured contents varied by subject as shown in Table IV.9.

Table IV.9 Variation In Discharge Summaries Produced Using Template

Document Section	Clerk	Resident	Resident
Admission Dx	Chronic Kidney Disease – NYD	Chronic renal failure - etiology uncertain	Chronic Kidney Disease-NYD
Health Status	Fully active	Fully active	Some restrictions
Comorbidity	5 entries	6 entries	4 entries
Operations	Renal Biopsy	Ultrasound guided kidney biopsy	Renal biopsy
Lab Data	35 lab results	59 lab results	88 lab results
Medications	12 entries	10 entries	12 entries
Course in Hospital	87 words	84 words	268 words

IV.B.3 Analysis Of Narrative Entries

The orientation of a discharge summary should be as a tool that supports medical work as a "social, interactive process" (53). The clinical insight was expressed through narrative. Rector's finding that "pragmatic clinical conventions often do not conform to general logical or linguistic paradigms" (29), was apparent in artifacts produced for the Transcription versus Template study. As an example, the statement by subject 58797, "His anemia was stable at 101", could be interpreted by a human as referring to the hemoglobin value. The task of programming a computer to make that association is more problematic.

The narrative entries for the three subjects who completed the Transcription versus Template study are given for both versions for their *Course in Hospital* description. The data entry via the template indicated some misuse of homonyms. Typographical errors were apparent. There was congruence between the two versions by the same subject, but congruence across subjects was less apparent.

> *[24140 Transcription] Mr. Irving had an ultrasound-guided renal biopsy conducted on November 7, 2002 which he tolerated quite well with no complications. The pathology report indicated severe nephrosclerosis but diabetic nephropathy was not prominent. The patient was educated on the topics of peritoneal dialysis and hemodialysis treatments while in the hospital. The patient showed no signs of uremia and was asymptomatic at this time and therefore did not require dialysis at this time. The dietician met with the patient and gave him appropriate diet information while on the ward.*
>
> *[24140 Template] Patient did quite well in hospital. Had renal biopsy because of unknown etiology of combination of a rising serum creatinine and blood in urine. Biopsy was preformed on November 11, 2002 to rule out possible glomerulonephritis which was tolerated well. The patient was given formal education on the topics of PD dialysis and Hemodialysis. Nutrition met with patient and diet was reviewed. Pathology of biopsy should severe nephrosclerosis. Serology tests were negative. Patient was asymptomatic on discharge with no uremia. No dialysis is required at this time.*
>
> *[58797 Transcription] In order to further determine whether there was a glomerulonephritis underlying Mr. Irving's acute renal failure, he underwent an ultrasound-guided kidney biopsy. There were no acute sequelae following the procedure. The initial report of the biopsy indicated that there was marked wrinkling of the basement membrane, as well as a severe tubular atrophy with interstitial inflammation and fibrosis. Immunofluorescence was negative. The diagnosis from the biopsy was of severe nephrosclerosis and that features of diabetic nephropathy were not prominent. This was in keeping with an etiology of his long-standing, poorly controlled hypertension.*

[58797 Transcription continued] Throughout his visit, Mr. Irving was treated for risk factor management and his blood pressure medication was adjusted upwards. He was continued on his Lipitor as well as all of his agents for hypertension. His anemia was stable at 101 with a normal MCV. There was no clear source of blood loss and it was thought that his anemia might be related to his chronic renal failure.

[58797 Transcription continued] Because it appeared that his kidney disease did not have a reversible etiology, both forms of hemodialysis including peritoneal and hemodialysis were discussed with the patient today. We also discussed with him through the nutritionist, no added salt diets with a limited phosphorus uptake.

[58797 Template] Mr. Irving was admitted to rule out a glomerulonephritis and further investigate his acute on chronic renal failure. He was started on Tums to control his phosphorous levels, bicarbonate orally to supplement his low CO2, and Alce with c daily. His creatinine increased to the mid 600s (crCl about 18 ml/min) over the course of his visit, with urea in the 30s. While he did not have symptoms of uremia, he was monitored closely. Also of note is his chronic anemia with low % saturation, perhaps secondary to his renal disease. He was started on Fe supplementation. Serologic workup did not suggest an infectious, connective tissue, or autoimmune reason for Mr. Irving's kidney disease. Renal biopsy was performed with no negative sequelae. It showed severe nephrosclerosis and some interstitial inflammation. Because the nephrosclerosis is not reversible and he was developing signs and symptoms of end stage renal disease, dialysis, both hemo and PD, were discussed with Mr. Irving. He was also given education about dietary restrictions related to renal disease, including no added salt and low phosphorous. Mr. Irving's other risk factors for cardiovascular disease were addressed in hospital. His diabetes was stable with a good HGBA1C. His lipid profile was less than satisfactory and we recomment outpatient followup. Mr. Irving did have elevated blood pressure throughout his visit. He was switched from Norvasc to Diltiazem during his visit. Mr. Irving was fully functional during his visit, and returned home needing no further home support at this time. He will discuss his hemodialysis options with his wife and make decisions in this regard in consultation with Dr. Soroka.

[88065 Transcription] Mr. Irving was admitted to the Nephrology Ward from clinic. He was started on a low salt, low cholesterol diet. Routine lab work was ordered and his ASA was held. The plan was to have a kidney biopsy performed. He was seen by nutrition during his admission who recommended 80 g protein 80 g sodium diet per day as well as a heart healthy diet. Just prior to the renal biopsy he was given 20 mg IV of DDAVP and some sodium bicarbonate 1 g PO bid. Renal biopsy was performed on November 7, 2002. A copy of this surgical pathology report will be forwarded to you, however, in summary, the pathologist felt that the features of diabetic nephropathy were not prominent in this specimen. However, he did not severe nephrosclerosis.

[88065 Template] Mr. Irving was admitted to Nephrology Ward. He was started on all his home medications, with the exception of his ASA. This was held for the upcoming biopsy. Mr. Irving was also started on a low salt, low protein diet. Mr. Irving was given DDAVP 20mg IV over 20 minutes and NaHCO3 1g PO BID prior to his biopsy. He was also started on Albee with C PO OD. Mr. Irving had his biopsy performed on Nov 7, 2002. He had no post-op complications.

IV.B.4 Paper Chart Representation In Clinical Document Repository

Each page of the patient chart was represented as a document using HL7 Clinical Document Architecture (CDA). There were 52 hand-written pages, and 20 printed pages. Each page was scanned so the document image could be referenced. A CDA document is considered compliant if the required fields are entered in the CDA Header (ClinicalDocument namespace, typedID, id, effectiveTime, confidentialityCode, recordTarget, author and custodian). A description of the document could be captured in the *summary,* an ActRelationshipType with classCode="SUMM". The subjects were entered into the *summary* section using their SNOMED CT code and display name, and the CDA Headers then formed the document index for the chart page in the CDA Repository. Object identifiers (OID) in the coded fields were registered with HL7 Inc. The OID, *2.16.840.1.113883.3.*36, was registered to Dalhousie University. Figure IV.13 gives the XML coding for the handwritten dischargeMedicationForm1.xml in the patient chart.

Figure IV.13 XML For Patient Chart Referent For Terazosin

```
<?xml-stylesheet type='text/xsl' href='IMPL_CDAR2.xsl'?>
<ClinicalDocument xmlns='urn:hl7-org:v3'>
<!-- CDA Header -->
 <realmCode code='CA'/>
 <typeId extension="POCD_HD000040" root="2.16.840.1.113883.1.3"/>
 <id assigningAuthorityName="2.16.840.1.113883.3.36" displayable="false"
extension="0001"/>
 <code code='X-HAD'  codeSystem='2.16.840.1.113883.6.1' />
 <title>Discharge Medication Form1</title>
 <effectiveTime value='20021112'/>
 <confidentialityCode code="N" codeSystem="2.16.840.1.113883.5.25"/>
 <languageCode code='en-US'/>
 <setId extension='999021'  root='1.3.6.4.1.4.1.2835.1'/>
 <versionNumber value='1'/>
<!-- Record Target: Patient in whose record the clinic letter is filed -->
<recordTarget>
   <patientRole>
    <id extension="0001234567" root="2.16.840.1.113883.3.36"/>
    <patient>
     <name>
      <prefix>Mr.</prefix>
      <given>B...</given>
      <family>I...</family>
     </name>
     <administrativeGenderCode code="M" codeSystem="2.16.840.1.113883.5.1"/>
     <birthTime value="19330630"/>
    </patient>
    <providerOrganization>
     <id extension="QEIIHSC" root="2.16.840.1.113883.3.36"/>
     <name>Queen Elizabeth II Health Sciences Centre</name>
    </providerOrganization>
   </patientRole>
  </recordTarget>
 <author>
   <time value='20021112'/>
   <assignedAuthor>
    <id extension='1' root='1.3.6.4.1.4.1.2835.1'/>
    <assignedPerson>
     <name>
      <given>Discharging</given>
      <family>Enterer</family>
      <suffix>RN</suffix>
     </name>
```

```xml
    </assignedPerson>
   </assignedAuthor>
  </author>
<custodian>
   <assignedCustodian>
     <representedCustodianOrganization>
       <id extension='1' root='1.3.6.4.1.4.1.2835.3'/>
       <name>Capital District Health Authority</name>
     </representedCustodianOrganization>
   </assignedCustodian>
  </custodian>
  <subject typeCode="SUMM">
   <description>
       <text>Hytrin 2mg po qhs</text>
       <code codeSystem="2.16.840.1.113883.6.96" codeSystemName="SNOMED CT"
     displayName="terazosin" code="129484001"/>
   </description>
  </subject>
<!-- CDA Body -->
  <component>
    <nonXMLBody>
       <text mediaType="image/jpeg">
       <reference
value="http://healthinfo.med.dal.ca/HealthInfoCDA/ckd/images/My%20Pictures/discharg
emed1/dischargemed1.jpg"/>
     </text>
   </nonXMLBody>
  </component>
</ClinicalDocument>
```

IV.B.5 Retrieval And Reuse

HL7 CDA documents were expressed using XML. The XML Style Language (XSL) was used to get human-readable formats. The XSL could be written to locate data fields and transform them for other purposes. This facilitated transforming from one HL7 CDA form, i.e., discharge summary, to another, i.e., Care Record Summary record for the patient. The set of document sections that were common were: Diagnosis, Allergies, Immunizations, Social History, Family History, Vital Signs, Lab Tests, Medications, Procedures, and Plan of Care. The process of aligning between the discharge summary and patient health record CDA implementations helped improve conformance with the HL7 specifications. It confirmed that we could populate the longitudinal patient record from multiple encounters.

The transformation of content in the electronic discharge summary into a CORR Initial Registration form was accomplished using XSL. The XSL enabled reuse of the discharge summary contents for another purpose, similar to the transformation of information into the Care Record Summary record for patients.

Section A of the CORR Initial Registration form was Personal Identification; Section B was Pre-Dialysis and Initial Blood Work; Section C was Initial and Intended Dialysis Treatment; Section D was Height and Weight; and Section E was Primary Diagnosis and Risk Factory History.

Table IV.10 showed that all beta-testers provided the required data fields for Section B but there were minor differences in the lab values because of the availability of multiple results.

Table IV.10 Blood Work For CORR Initial Registration Form

CORR Initial Registration Form	Nurse 1	Nurse 2	Resident	Nephrologist
Haemoglobin (g/L)	98	99	98	98
Creatinine (µmol/L)	636	636	636	636
Urea (mmol/L)	32	32	32	28.6
Serum Bicarbonate (mmol/L) /CO_2	22	22	22	19
Serum Calcium (mmol/L)	2.42	2.42	2.42	2.42
Serum Phosphate (mmol/L)	1.75	1.75	1.75	1.75
Serum Albumin (g/L)	39	39	39	39

The evaluation of the reuse for co-morbidities is complex because they are grouped differently depending on data reuse, by either the WHIC-CDM system, CORR or CIHI Discharge Abstract. The diagnosis types for the CIHI Discharge Abstract were M (Most Responsible Diagnosis); 1 (Pre-Admit Comorbidity); 2 (Post-Admit Comorbidity); 3 (Secondary Diagnosis); and 4 (Admitting Diagnosis). Section E of the CORR Initial Registration form grouped comorbidities and risk factors differently from that needed for CIHI Discharge Abstract and for WHIC-CDM. The medical education resource, *Diabetes: An Instant Reference*[21], also labeled the complications of diabetes in a different way than either WHIC-CDM or CIHI. Table IV.11 illustrates the overlaps and the differences among the three categorization approaches.

Table IV.11 Comorbidity, Risk Factors And Complications Of Chronic Disease

WHIC-CDM	**CORR**	**Diabetes: An Instant Reference**
Sexual function	Not present	Erectile Dysfunction
Foot disorders	Not present	Foot Problems
Congestive heart failure (CHF)	Angina; Myocardial infarct; Coronary artery bypass grafts/ angioplasty; Peripheral vascular disease	Macrovascular – Heart Problems
Left ventricular hypertrophy (LVH)	Not present	Not present
Hypertension	Receiving medications for hypertension	Macrovascular - Hypertension
Dyslipidemia	Not present	Macrovascular - Hyperlipidemia
Diabetes	Diabetes type 1; Diabetes type 2	Diabetes Mellitus
Chronic Kidney Disease (CKD)	CORR is a register for renal replacement therapy, so all cases have a chronic kidney disease	Nephropathy
Depression	Not present	Not present
Vascular Disease	Cerebrovascular disease Recent history of pulmonary edema	Macrovascular Foot Problems – Peripheral Vascular Disease
Metabolic Syndrome	Diabetes type 1; Diabetes type 2; Receiving medications for hypertension	Metabolic Syndrome

21 http://informatics.medicine.dal.ca/diabetes

WHIC-CDM	CORR	Diabetes: An Instant Reference
Other Diagnoses (specify)	Malignancy existing prior to first treatment; Chronic obstructive lung disease; Other serious illness that could shorten life expectancy to >5 years; Current smoker	Hypoglycemia Hyperglycemia
Neuropathy	Not present	Neuropathy
Retinopathy	Not present	Retinopathy
Impaired Glucose Tolerance (IGT)	Not present	Impaired Glucose Tolerance (IGT) & Impaired Fasting Glucose (IFG)

A process was required to generate CORR's Section E information about the 13 risk factors or comorbidities. For purposes of reuse, the unstructured data available from the "reason for medication" and the "previous medical history" helped confirm the status for Section E. The status choices were yes, no and unknown. The CORR form asked not only if a condition existed but whether the patient was receiving medication for the condition. On data entry, the clinician was prompted to enter the "Reason for a medication". This was free text. In order to standardize the medication events the HL7 Template normalized the medication events using the HL7 Clinical Statement Model. The reason for a medication could be inferred from the ontological relationships among concepts in SNOMED's disorders and product classes.

In the clinical pragmatic expressions in medical education resource, *Diabetes: An Instant Reference,* the reader is instructed to treat hypertension using ACEi or ARB[22]. ARB refers to alpha-adrenergic blocking agent and ACEi to angiotensin-converting enzyme inhibitor agent. The SNOMED ontological relationships are used to infer whether or not a patient is taking medication for hypertension. In this way, we are able to infer that the Nova Scotian patient is taking medication for hypertension by inferring the reason for Hytrin, Cardizem SR and Norvasc medications.

1. *Hytrin* has-generic-name *terazosin*, which is-a *alpha 1 adrenergic blocking agent*

2. *Cardizem SR* has-generic-name *diltiazem*, which is-a *calcium channel blocking agent*

[22] http://informatics.medicine.dal.ca/diabetes/complications/nephropathy/DiabetesandKidney.ppt

3. *Norvasc* has-generic-name *amlodipine*, which is-a *calcium channel blocking agent*

4. *Acebutolol* is-a *beta 1 blocking agent*

The contextual attributes of the Boundary Infostructure were evaluated at a system level using the CHAMP Community of Learners framework. The artifacts were produced by Clinicians; shaped by the classification systems and standards produced by Health informaticians; and coded by Administrators. It was envisioned that prototypical cases would be sought by Medical educators and Patients would communicate with their clinician using the Care Record Summary as a common point of reference.

In this formative evaluation, we confirmed that we could support all five contexts of use to some extent.

IV.B.6 Conceptual Design For The Chronic Kidney Disease Topic Map

This research produced a testbed based on the conceptual model for the Chronic Kidney Disease Topic Map (Figure VI.14).

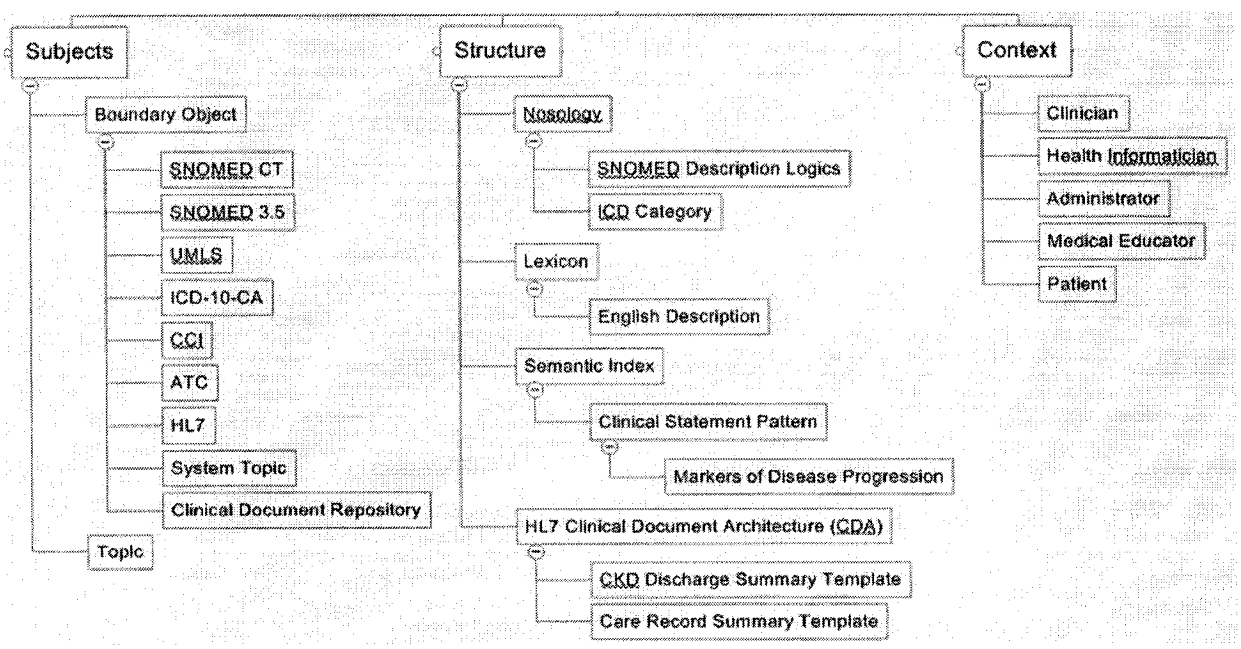


Figure IV.14 Conceptual Model For Chronic Kidney Disease Topic Map Version 1

Chapter V: Study Two: Clinical Data Warehouse Discharge Records

This study was conducted to test the clinical pragmatics, usefulness and usability hypotheses, constrained terminology, commensurability of different classifications and common ground hypotheses. The ontology process was applied to identify the constrained terminology, categorize it using boundary objects and interpret it for multiple user contexts.

The study goal was the elaboration of topic map and HL7 methods for the representation of data from Centre Informatis, de Recherche Evaluative en Services et Soins de Sant (CIRESSS) clinical data warehouse. The data from study one (Chapter IV) is merged with the data from this study to produce the integrated Chronic Kidney Disease Topic Map and Clinical Document Repository for the boundary infostructure. The overall evaluation of the boundary infostructure is given in Chapters VII and VIII.

V.A Study Two Methods

The title of this study was *Utilisation de Topic maps et HL7 dans CIRESSS*. The author and Andriy Moshyk, Université de Sherbrooke and a fellow trainee in the CIHR PhD/Postdoc Strategic Training Program in Health Informatics (CHPSTP), were co-investigators for the study. Paul Fabry, another CHPSTP Trainee, wrote the query to obtain the CIRESSS dataset. The study hypothesis was, "*A Topic Map that is based on standard vocabulary sources can index prototypical cases from CIRESSS and discover relationships that will improve the HL7 Template for the Chronic Kidney Disease Discharge Summary.*"

The objectives were:

1. index CIRESSS cases using Topic Map representation of keywords and their relationships from standard vocabularies;
2. organize information entered into Discharge Summary using Topic Map;
3. identify similar cases based on Topic Map.

V.A.1 Query For Cases In CIRESSS Clinical Data Warehouse

The intension was to identify cases in the CIRESSS clinical data warehouse with a similar diagnostic profile to the Halifax patient who was the focus for study one, Transcription versus Templates (Chapter IV). That patient had chronic kidney disease, diabetes and hypertension. His CIHI Discharge Abstract was coded to ICD-10-CA diagnoses *"N18.9 Chronic Renal Failure Unspecified", "I12. Hypertensive Renal Disease", "E11.220 T2 DM W ESRD ADEQ CONTR W DIET", "E78.5 Hyperlipidaemia, Unspecified", "D50.9 Iron Deficiency Anaemia Unspecified", "N17.9 Acute Renal Failure Unspecified"*. The query generated for CIRESSS had the following diagnoses:

(ME_DIAGNOSTIC.ECLE_ME_CIM9__DIAGNOSTIC IN ('250.40') AND ME_DIAGNOSTIC_2.ECLE_ME_CIM9__DIAGNOSTIC IN ('403.91') AND SN_SNOMED_LOG.CODE_SNOMED IN ('D3-02000', 'DB-61030', 'DB-63130')).

CIM9_DIAGNOSTIC stood for ICD-9. In Nova Scotia, ICD-9-CM was used for Medical Services Insurance claims, and code 250.40 stood for *"Diabetes with renal manifestations"*. In Quebec, code 250.40 stood for *"DIABETE AVEC COMPLICATIONS OCULAIRES, ADULTE"* in French or *"Diabetes with ophthalmic manifestations"* in English. The difference was explored and led to the realization that the mappings varied by version as shown in Table V.1.

Table V.1 Differences In ICD-9 And ICD-9-CM for Code 250.x

Code	ICD-9	ICD-9-CM
250.0	Diabetes mellitus without mention of complication	Diabetes mellitus without mention of complication
250.1	Diabetes with ketoacidosis	Diabetes with ketoacidosis
250.2	Diabetes with other coma	Diabetes with hyperosmolarity
250.3	Diabetes with renal manifestations	Diabetes with other coma
250.4	Diabetes with ophthalmic manifestations	Diabetes with renal manifestations
250.5	Diabetes with neurological manifestations	Diabetes with ophthalmic manifestations
250.6	Diabetes with peripheral circulatory disorders	Diabetes with neurological manifestations

ICD-9 code 403.91 stood for *"NEPHROPATHIE DUE A HTA +INS.RENALE (401+585 OU 586)"* in French in the CIRESSS dataset. Codes 401, 585 and 586 stood for *"Essential* *hypertension", "Chronic renal failure"* and *"Renal failure, unspecified"*, respectively. Code 403 stood for *"Hypertensive renal disease"* in ICD-9[23] and code 403.91 stood for *"Hypertensive renal disease Unspecified with renal failure"* in ICD-9-CM[24].

SN_SNOMED stood for SNOMED 3.5. The SNOMED code D3-02000 was interpreted by the 2004 version of SNOCODE software (158) in English and French as standing for *"HTA", "High Blood Pressure", "Hyperpiesia", "Hyperpiesis", "Hypertension, NOS", "Hypertensive vascular degeneration", "Hypertensive vascular disease", "degenerescence vasculaire hypertensive", "hyperpiesia", "hypertension", "hypertension arterielle", "maladie vasculaire hypertensive", "maladie hypertensive".*

The SNOMED code D3-02000 was mapped in the 20070131 version of SNOMED CT to code 38341003. The set of descriptions that were mapped to code 38341003 in SNOMED CT, file sct_descriptions_20070131.txt, were: *"Hypertensive disorder", "BP - High blood pressure", "Systemic arterial hypertension", "Raised blood pressure", "Hypertensive vascular degeneration", "Hyperpiesis", "High blood pressure disorder", "HTN – Hypertension", "HBP - High blood pressure", "BP - High blood pressure", "BP+ - Hypertension", "Elevated blood pressure", "HT – Hypertension", "High blood pressure", "Hyperpiesia", "Hypertension", "Hypertensive vascular disease", "Hypertensive disorder", systemic arterial (disorder)", "Hypertensive disease", "Hypertension, NOS", "Hypertensive disease, NOS", "Raised blood pressure (disorder)".*

The SNOMED code DB-61030 was mapped in the 20070131 version of SNOMED CT to code 44054006. The set of descriptions that were mapped to code 44054006 in SNOMED CT, file sct_descriptions_20070131.txt, were: *"Diabetes mellitus type 2", "Non-insulin dependent diabetes mellitus", "Diabetes mellitus type II", "Type 2 diabetes mellitus", "NIDDM - Non-insulin dependent diabetes mellitus", "Non-insulin-dependent diabetes mellitus", "Maturity onset diabetes mellitus", "Type II diabetes mellitus", "Diabetes mellitus - adult onset", "NIDDM", "Diabetes mellitus type 2 (disorder)", "NCDMM".*

The SNOMED code DB-63130 was mapped in the 20070131 version of SNOMED CT to code 83469008. The set of descriptions that were mapped to code 83469008 in SNOMED

[23] ftp://ftp.cdc.gov/pub/Health_Statistics/NCHS/Publications/ICD-9/
[24] ftp://ftp.cdc.gov/pub/Health_Statistics/NCHS/Publications/ICD9-CM/2003/

CT, file sct_descriptions_20070131.txt, were: *"Hyperinsulinaemia"*, *"Hyperinsulinemia"*, *"Hyperinsulinism (disorder)"*, *"Hyperinsulinism, NOS"*.

The query results returned fields: pseudonymized patient identifier, key to join tables, identifier, date of admission, date of discharge, visit number, SNOMED 3.5 code, SNOMED nomenclature, ICD9 code, ICD9 description, principal diagnosis indicator, CCP (Canadian Classification of Diagnostic, Therapeutic and Surgical Procedures) code, CCP description, procedure, age, sex, service, stage number (each visit consists of one or more than one stage), department and specialty.

V.A.2 Query For Laboratory Data From CIRESSS Cases

A query generated for a subset of the CIRESSS cases returned the following laboratory fields: lab result outcome indicator, lab order, date, time, lab result, lab result line number, lab result value, comment and lab result reference range.

V.B Normalize CIRESSS Data Using HL7 And Terminology Systems

The tabular data obtained from CIRESSS required interpretation at the field level and the content level. The goal was normalization of diagnoses, procedure and laboratory results. Normalized results ensured that study two data could be merged with study one data (Chapter IV) to form the boundary infostructure components, Chronic Kidney Disease Topic Map and Clinical Document Repository. The normalization method was the Clinical Statement pattern which was the common foundation for the HL7 Clinical Document Architecture templates (30). The HL7 Template for the Chronic Kidney Disease Discharge Summary designed for this research supported data fields, such as medications, that were not available from CIRESSS.

The process required translation from French to English, translation from descriptive text to coded concept, transformation of entries into clinical statement patterns and structuring entries in HL7 CDA documents for storage in the Clinical Document Repository. The only coded fields in the CIRESSS dataset were the diagnoses and the procedures. Other data fields had French text descriptions. The process was:

1. Translation from French to English. The three methods used were manual translation by bilingual personnel; automatic matching of French description for SNOMED 3.5

codes generated from natural language processing of English text through a time-limited licensed copy of SnoCode[25]; and manual mapping to UMLS Knowledge Sources Server[26] using English for the query and French for the results.

2. Transformation to lab result patterns. Seventy-one of the 118 lab patterns from study one were updated with their French descriptions from the CIRESSS dataset. The attributes were labtestcode, titre_champ, labtestdescription, labtestlow, labtesthigh, labtestunit, SNOMED CT, sfilename, SNOMED 3.5, UMLS. The sfilename was the URL required for linking from the HL7 CDA to a subject reference and from the Chronic Kidney Disease Topic Map to a subject resource.

3. Transformation to diagnoses patterns. The French descriptions were added to the diagnoses table. The mappings among ICD-9, ICD-9-CM, ICD-10-CA, UMLS and SNOMED CT were made. The attributes for a diagnosis pattern were French_description, English_description, ICD-9-CM, ICD-10-CA, UMLS, ufilename, SNOMED CT, snomedfilename. The ICD-9-CM to SNOMED CT mapping was available as part of the licensed copy from SNOMED International Organization. The ICD-9-CM to ICD-10-CA mappings were made using UMLS as the switching language.

4. Normalization of clinical documents for Clinical Document Repository. The HL7 Care Record Summary template was used for normalization of document sections and the CDA Quick Start Guide V1.1[27] for implementation instructions. Each CDA instance was indexed by the HL7 Clinical Statement Patterns for lab results, diagnoses and procedures and the index stored in the CDA Header.

V.C.1 Constrained Terminology For Subjects In Topic Map

The constrained terminology was all field attributes in the mySQL tables used to normalize the CIRESSS dataset, all instance entries in the mySQL tables used to generate the HL7 Clinical

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25 http://www.medsight-info.com/en/Products/Snocode.htm
26 http://umlsks.nlm.nih.gov
27 http://www.alschulerassociates.com/cda/?topic=quick-start-guides

Statement entries for the HL7 CDA documents, all semantic indices and the terms that were identified from a semantic analysis of all the items in the Chronic Kidney Disease Text Corpus (Appendix A).

V.C.2 Nosological, Lexical, Semantic And HL7 Structures In Topic Map

The nosology structure was the classification of a clinical concept in SNOMED, an analytico-synthetic classification, and/or ICD, a family of enumerative classifications.

The lexical category structure was language, which included English and French. The UMLS Metathesaurus was used as a lexical resource and functioned as a switching language for subjects coded to HL7, ICD-9-CM, ICD-10-CA, SNOMED CT or SNOMED 3.5.

A semantic index was designed for the purpose of identifying similar cases in the Clinical Document Repository from study one (Halifax jurisdiction) and/or study two (Sherbrooke jurisdiction). The semantic index was designed from HL7 Clinical Statement patterns used for triage and chronic disease management, disease groupings, procedure groupings and complications groupings.

The clinical pragmatic patterns were those facilitators that enable patient triage by the Divisions of Endocrinology (Figure V.1) and Nephrology (Figure V.2), as expressed in the Department of Medicine Triage Process and Wait Time Standards for Ambulatory Care, Capital Health, Nova Scotia[28].

[28] http://dom.medicine.dal.ca/waitlists/CHWaitTimesSept06.pdf

Triage Category	Examples (not all inclusive)	Process	Facilitators	Standard Wait Time	*Current Wait Time
Emergent	• Severe hyperthyroidism • Diabetic ketoacidosis • Severe hypoadrenalism • Severe hypercalcaemia	Call (902) 473-2220 "Endocrinologist on Call"	Appropriate lab data e.g. • fT4, Ca, FBG	Within 1 day	No data
Urgent	• Diabetes A1c >12 (new or different) • Newly diagnosed Diabetes Mellitus • Severe Hyperlipidemia • Hypercalcemia >3.00 • Hyperlipidemia TG >10 • Hypoadrenalism, • Hypopituitarism	Fax referral form (Appendix 1) marked **"URGENT"** to: (902) 473-5912	Appropriate lab data e.g. • FBG, BP, A1c, Lipid profile, TSH, fT4	Within 1 week	0.8 weeks
Semi-Urgent	• Hyperthyroid and hypothyroid • Pituitary tumor • Thyroid lump • Diabetes A1c >7 • Hyperlipidemia – high risk • Hypercalcemia 2.8 – 3.0	Fax referral to: (902) 473-5912	Appropriate lab data e.g. • Hyperthyroid or hypothyroid referrals must include TSH & fT4 results • FBG, BP, A1c, Lipid profile	Within 4 weeks	5.0 weeks
Non-Urgent	• Normal thyroid function and no thyroid lumps • Hirsutes • Infertility • Obesity: no complications • Hyperlipidemia: low risk	Fax referral to: (902) 473-5912 or Mail referral to: Division of Endocrinology 7 North Victoria Bldg. QEII HSC,1278 Tower Rd Halifax, NS B3H 2Y9	Appropriate lab data e.g. • FBG, BP, A1c, Lipid profile, TSH, fT4	Within 12 weeks	10.3 weeks

Figure V.1 Facilitators For Triage By Endocrinologists

Triage	Examples Category	Process (not all inclusive)	Facilitators	Standard Wait Time	*Current Wait Time
Emergent	• Life threatening uremic symptoms e.g. marked hyperkalemia, pulmonary oedema, pericarditis	Immediate referral to the nearest Emergency Department Phone (902) 473-2220 and ask for the "Nephrologist on call"		<1 day	No data
Urgent	• End stage renal disease • Rapid decline in renal function over days to weeks • Severe uncontrolled symptoms of kidney disease	Fax: (902) 473-2675 Mark "Urgent" Phone (902) 473-2220 and ask for the nephrologist on call	Supply: • Symptoms • Medications • Blood pressure • Urinalysis • Recent lab results (serum creatinine, urea, electrolytes including chloride and HCO_3, calcium, albumin, phosphorus) Where possible: • Serum protein electrophoresis • 24 urine for protein, Na^+, creatinine • Renal ultrasound	Within 5-7 days	6.3days
Semi-Urgent	• Subacute renal failure, with deterioration over weeks to months • Mild to moderate symptoms of kidney disease	Fax: (902) 473-2675 Or Mail: Division of Nephrology 5090 ACC, QEII Health Science Centre 5820 University Ave. Halifax, NS B3H 1V8	Supply: • Symptoms • Medications • Blood pressure • Urinalysis • Recent lab results (serum creatinine, urea, electrolytes including chloride and HCO_3, calcium, albumin, phosphorus) • Serum protein electrophoresis • 24 urine for protein, Na^+, creatinine • Renal ultrasound	4-6 weeks	2.4 weeks
Non-Urgent	• Stable, chronic renal failure, decline over months to years • Mild symptoms or signs of kidney disease	Fax: (902)473-2675 Or Mail: Division of Nephrology 5090 ACC, QEII Health Science Centre 5820 University Ave Halifax, NS B3H 1V8	• As above	> 12 weeks	3.0 weeks

Figure V.2 Facilitators For Triage By Nephrologists

The diagnostic categorization scheme for disease groups was the Charlson-Deyo Comorbidity Index[29]. This indexing scheme was used with the Canadian Organ Replacement Register data in the preparation of Ontario's practice atlas[30]. The 17 disease groups in the Charlson-Deyo scheme were: Myocardial Infarction, Congestive heart failure, Peripheral vascular disease, Cerebrovascular disease, Dementia, Chronic pulmonary disease, Rheumatologic disease, Peptic ulcer disease, Mild liver disease, Diabetes (mild to moderate), Hemiplegia or paraplegia, Moderate or severe renal disease, Diabetes with complications, Malignancy, Moderate or severe liver disease, Metastatic solid tumour, and AIDS[31] (Table V.2). The disease category index vector was entered into the CDA Header of the HL7 Care Record Summary for each hospital visit by each patient.

Table V.2 Charlson Index

Group	Condition	ICD-9 Codes in CIRESSS Dataset
1	Myocardial Infarction	410.9, 410.93, 410.934, 412.9
2	Congestive Heart Failure	428, 428.1, 428.9
3	Peripheral Vascular Disease	440, 440.1, 440.2, 440.9, 441.4, 443.8, 447.1, 441.4, 447.1, V43.40
4	Cerebrovascular Disease	431.91, 433.1, 433.31, 434.9, 435.9, 436.91, 436.92, 437.8, 438.9
5	Dementia	290, 290.4, 290.8
6	Chronic Pulmonary Disease	416.9, 490.9, 491.1, 491.9, 493.9, 493.91, 493.92, 494.9, 496.9
7	Connective Tissue Disease	710.4, 714, 725.9
8	Peptic Ulcer Disease	531.9, 532.4
9	Mild Liver Disease	570.9, 571.5, 571.8, 572.8, 573.3
10	Diabetes without Complications	250.2
11	Diabetes with Complications	250.3, 250.4, 250.5, 250.6, 250.7, 250.701, 250.703, 250.704, 250.705, 250.791
12	Paraplegia and Hemiplegia	344.4
13	Renal Disease	583.1, 583.2, 585.9, 586.91, 588.8, V42.00, V42.01, V45.1, V56.8
14	Cancer	150.9, 151.9, 171.5, 189
15	Moderate or Severe Liver Disease	572.8, 573.3
16	Metastatic Carcinoma	196.1, 197, 197.2, 198.5, 198.7
17	AIDS/HIV	N/A

[29] http://www.umanitoba.ca/centres/mchp/concept/dict/charlson.index.html
[30] http://www.ices.on.ca/file/DM_Chapter8.pdf
[31] http://secure.cihi.ca/cihiweb/en/reports_corrinsites_dec2001_define_t1_e.html

There were three procedure classification systems used in data collected by CIHI. The two classification schemes used in the hospital data analyzed for this research were: Canadian Classification of Diagnostic, Therapeutic and Surgical Procedures (CCP) and Canadian Classification of Interventions (CCI)[32]. The procedures were categorized by chapter. The CCP chapters that interest this research were: Chapter I (01-13), Miscellaneous Diagnostic and Therapeutic Procedures; Chapter VIII (47-51), Operations on the Cardiovascular System; Chapter X (54-66), Operations on the Digestive System and Abdominal Region; Chapter XI (67-71), Operations on the Urinary Tract; and, Chapter XV (88-96), Operations on the Musculoskeletal System. The CCI chapter that was pertinent is 1.PA.^^ to 1.PZ.^^ which was mapped to Chapter XI of CCP. The procedures were clinical activities that were associated with complications of diabetes and chronic kidney disease.

The complications categorization scheme is based on six categories of diabetes complications. These were: macrovascular; nephropathy; neuropathy; erectile dysfunction; retinopathy; and foot problems[33]. Some of the complications, such as foot problems, were reflected in both diagnoses and procedure codes. The code set attributed to each complication was taken from the National Diabetes Surveillance System (192) and the ICD-9 and ICD-10-CA coding rules.

The testing of the common ground hypothesis required an ability to identify CDA instances with similar disease, procedure and complications profiles. This was done with the semantic indexing approach. The research examined if we could make commensurable the different classifications. It used both ICD-9-CM and ICD-10-CA in categorizing cases by disease group and both CCI and CCP for categorizing cases by procedures group.

V.C Populating The Chronic Kidney Disease Topic Map

Two sets of hospital data were normalized to HL7 CDA, stored in the Clinical Document Repository and indexed. Capital Health's CIHI Discharge Abstracts (N=1 patient for 2 visits) was coded to ICD-10-CA for diagnoses and CCI for procedures. Sherbrooke's CIRESSS data (N=160 patients for 302 visits) was coded to ICD-9 for diagnoses and CCP for procedures.

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[32] http://secure.cihi.ca/cihiweb/dispPage.jsp?cw_page=codingclass_ccicompare_e

[33] http://informatics.medicine.dal.ca/diabetes/

Each CDA instance was evaluated for the clinical pragmatic patterns asserted in the Chronic Disease Management (5) data standard, Capital Health's Department of Medicine triage process[34] and the complications of diabetes as defined for the National Diabetes Surveillance system (193).

The semantic index was evaluated for its ability to capture clinical pragmatic patterns and to generate a patient journey from multiple hospital visits by the same patient. The pragmatic attributes of the Clinical Document Repository were evaluated for their ability to index each document by clinical pragmatic patterns, disease, procedure and complications categories, and document type. It was evaluated for its ability to relate similar patient cases to each other.

HL7 CDA documents were expressed using XML. The XML Style Language (XSL) was used to get human-readable formats. The XSL was written to locate data fields and transform them into the Care Record Summary record for patients.

The patient's problem was coupled with the pragmatic information for encounter facilitation. This was done using the HL7 Clinical Statement Model to express the specific patient's data in a manner that matched with the Department of Medicine's Triage system. By ensuring that the electronic health information that was needed was expressed the same way for all patients, we achieved semantic interoperability based on the specifications for the community-based physicians making the referrals, and the clinicians acting on the referrals. Administrators, such as the booking clerks, would act on the same information in scheduling appointments.

The two conditions were diabetes control as indicated by the HBA1c lab result and End Stage Renal Disease (ESRD). The lab data labels in the Triage document are mapped to the lab descriptions in the Capital Health's Specimen Collection Catalog and CIRESSS NOM_DE_LA_REQUETE and TITRE_CHAMP descriptions as indicated in Table V.3.

[34] http://dom.medicine.dal.ca/waitlists/CHWaitTimesSept06.pdf

Table V.3 Mapping Across Datasets For Lab Results

Facilitators	Specimen Collection	CIRESSS Descriptions
FBG (Fasting Blood Glucose)	Glucose AC, Serum (Note: the patient is not expected to fast during a hospital stay, so the lab results are Glucose in Urinalysis or Glucose Random)	Glucose sérique
A1c	HGB A1C	Hémoglobine A1c
Lipid Profile	Trigylcerides, Cholesterol, HDL-Cholesterol, LDL-Cholesterol (Calculated), CHOL/HDL Ratio	Triglycérides, Cholestérol total, Cholestérol-HDL, Cholestérol-LDL, Rapport C-LDL/C-HDL, Rapport CT/C-HDL,
TSH	Thyroid Stimulating Hormone	Thyrotropine sérique
fT4	Thyroxine, free/T4 Free	Thyroxine libre
Urinalysis	Urinalysis	Analyse d'urine macro/microscopie
Cr	Creatinine	Créatinine sérique
Urea	Urea, Serum	Urée sérique
Electrolytes	Electrolytes, Serum (Sodium, Potassium, Chloride, Total CO2/HCO3, Anion Gap)	Electrolytes sériques [Na, K, Cl]
Ca	Calcium, Serum	Calcium sérique
Albumin	Albumin, Serum	Albumine sérique
P04	Phosphorus, Serum	Phosphates sériques
24 Hr Urine	Urine Protein Electrophoresis	Electrophorèse des protéines urinaires
Serum protein electrophoresis	Protein Electrophoresis, Serum	Electrophorèse des protéines sériques

Table V.4 indicates the Endocrinology triage level based on HBA1c category and the Nephrology triage level based on the category of Chronic Kidney Disease for 18 hospital stays, 17 for Sherbrooke and 1 for Halifax.

Table V.4 Triage For Endocrinology/Nephrology Cases

Case	HBA1c	Facilitators-Endocrinology Glucose, A1c, Lipid Profile, TSH, fT4	ESRD	Facilitators-Nephrology Urinalysis, Cr, Urea, Electrolytes, Ca, Albumin, PO4, 24 Hr Urine, Serum Protein Electrophoresis
Q06039-1		Glucose, Lipid Profile		Urinalysis
Q06039-2				Urinalysis
Q06039-3		Glucose, Lipid Profile, TSH	Urgent	Urinalysis, Cr, Urea, Electrolytes, Ca, Albumin, PO4, 24 Hr Urine, Serum Protein Electrophoresis
Q61372-1				
Q61372-2				
Q61372-3		Glucose, Lipid Profile	Urgent	Cr, Urea, Electrolytes, Ca, Albumin
Q61372-4		Glucose, Lipid Profile	Urgent	Cr, Urea, Electrolytes
Q61372-5		Glucose	Urgent	Cr, Urea, Ca
Q61372-6	Semi-Urgent	Glucose, TSH, fT4	Urgent	Urinalysis, Cr, Urea, Electrolytes, Ca, Albumin, 24 Hr Urine
Q61965-1	Semi-Urgent	Glucose, A1c, Lipid Profile, TSH	Urgent	Urinalysis, Cr, Urea, Electrolytes, Ca, Albumin, P04, 24 Hr Urine
Q34501-1	Semi-Urgent	Glucose, Lipid Profile, TSH	Urgent	Urinalysis, Cr, Urea, Electrolytes, Ca, Albumin, P04, 24 Hr Urine
Q34501-2		Glucose	Urgent	Urinalysis, Cr, Urea, Ca, Albumin, P04
Q52165-1	Non-Urgent	Glucose, A1c, TSH, fT4	Urgent	Cr, Urea, Ca, P04, Serum Protein Electrophoresis
Q52165-2		Glucose	Urgent	Urinalysis, Cr, Urea, Ca, P04
Q52165-3				Cr, Urea, P04
Q52165-4		Glucose, A1c		Cr, Albumin
Q52165-5				Cr, Urea, P04
NS0093-1	Non-Urgent	Glucose, A1c, Lipid Profile, TSH	Urgent	Urinalysis, Cr, Urea, Electrolytes, Ca, Albumin, P04, 24 Hr Urine

A disease vector was generated for each hospital visit. These were compared across visits for the same patient to determine whether there was change over time that could be depicted as a patient journey. Based on the disease vector, for the 78 patients with multiple visits 13 exhibited no change and 65 exhibited change. For patients with multiple visits, the patterns may reflect disease progression of their chronic condition and resolution of acute conditions. Table V.5 shows a sample of the disease vector patterns with a comment on how the change was interpreted.

Table V.5 Patient Journey Based On Charlson Disease Groups

Patient ID	Disease Group Vector	Comment on Change over Time
1 (visit 1) 1 (visit 2)	00000100003010000 00100000003010000	Diabetes (group 11) and Renal Disease (group 13) unchanged; Comorbidity change from Chronic Pulmonary Disease (496.9 in group 6) to Peripheral Vascular Disease (440.9 in group 3)
10660 (visit 1) 10660 (visit 2) 10660 (visit 3) 10660 (visit 4)	00100000103010000 10100000103010000 00100000003010000 00100000004010000	Additional code for Diabetes with complications (group 11) on 4th visit; Myocardial Infarction (group 1) from 2nd visit no longer coded
14679 (visit 1) 14679 (visit 2)	00000000001020000 00000000001010000	Removal of code for Renal Disease on 2nd visit
57991 (visit 1) 57991 (visit 2) 57991 (visit 3)	00000000002010000 00000000002020000 00000000002010000	Additional code for Renal Disease
23198 (visit 1) 23198 (visit 2) 23198 (visit 3)	11100110002010000 01100000002010000 00100000002010000	Removal of codes for 3 problems (Myocardial Infarction, Chronic Pulmonary Disease and Connective Tissue Disease) on 2nd and subsequent visits
106039 (visit 1) 106039 (visit 2) 106039 (visit 3)	01000000002020000 01000000002020000 00000000002020000	Congestive Heart Failure (group 2) not coded for visit 3
261372 (visit 1) 261372 (visit 2) 261372 (visit 3) 261372 (visit 4) 261372 (visit 5) 261372 (visit 6)	00000000002010000 00000000002010000 10000000002020000 10000000002020000 00000000002020000 10000000002020000	Addition of Myocardial Infarction (group 1) and progression from 1 to 2 Renal Disease (group 13)
361965 (visit 1)	10000000003010000	Myocardial Infarction (group 1), 3 Diabetes Complications (group 11) and 1 Renal Disease (group 13)
434501 (visit 1) 434501 (visit 2)	00000000003020000 10000000003010000	Myocardial Infarction (group 1) on visit 2
852165 (visit 1) 852165 (visit 2) 852165 (visit 3) 852165 (visit 4) 852165 (visit 5)	00100000003020000 00110000003020000 00110000003020000 00110000003020000 00010000004020000	Peripheral Vascular Disease (Group 3-440.9) not coded visit 5; Additional Diabetes with Complications (Group 11-250.6 Diabetes with peripheral circulatory disorders)
NS0093 (visit 1)	00000000002010000	Two Diabetes with complications (Group 11) and one Renal Disease (Group 13)

There were 129 different disease vector patterns. Zipf's law describes the distribution of the usage of terms in text, and there was a somewhat regular pattern to the distribution (Table V.6). The Zipf formula is *Frequency x rank = constant.*

Table V.6 Disease Vector Pattern Frequencies

Rank	Frequency	Zipf	Vector
1	26	26	11|11|13|
2	14	28	3|11|11|11|13|
2	14	28	11|11|11|13|
4	13	52	3|11|11|13|
5	12	60	6|11|11|13|
6	10	60	2|11|11|11|13|
7	8	56	11|11|11|13|13|
8	6	48	11|11|13|13|
8	6	48	3|6|11|11|11|13|
8	6	48	2|11|11|13|
11	5	55	1|3|11|11|11|13|
11	5	55	1|11|11|11|13|
11	5	55	2|3|11|11|11|13|
11	5	55	2|11|11|13|13|
11	5	55	6|9|11|11|11|13|
16	4	64	6|11|11|11|13|
16	4	64	3|4|11|11|11|11|13|
16	4	64	3|3|11|11|11|13|
16	4	64	3|11|11|11|13|13|
16	4	64	2|6|11|11|13|
16	4	64	2|3|11|11|11|11|13|
16	4	64	1|2|11|11|11|13|
23	3	66	1|11|11|13|13|
23	3	66	11|11|11|11|13|
23	3	66	11|13|
23	3	66	2|6|11|11|11|13|
23	3	66	3|11|11|11|11|13|
23	3	66	3|5|11|11|11|13|
29	2	58	1|11|11|13|
29	2	58	1|2|11|11|13|
29	2	58	1|3|11|11|11|13|13|
29	2	58	1|6|11|11|13|
29	2	58	11|11|13|13|13|
29	2	58	11|11|13|14|
29	2	58	2|11|13|
29	2	58	2|3|11|11|13|
29	2	58	2|3|3|11|11|11|13|
29	2	58	2|4|5|11|11|13|
29	2	58	5|6|11|11|11|13|
29	2	58	6|11|13|
29	2	58	9|11|11|13|
42	1	42	(88 entries)

The disease vector patterns were a solution to the clinical pragmatics problem for retrieval of hospital cases with similar diagnostic patterns.

Another disease categorization scheme was the complications of diabetes mellitus. There were 6 complications categories: macrovascular, nephropathy, neuropathy, retinopathy, erectile dysfunction and foot problems. The code set for each complication (Table V.7) was taken from the National Diabetes Surveillance System (193) and ICD-9-CM coding rules.

Table V.7 Complications Of Diabetes Mellitus

Group	Subcategory	ICD-9 Codes in CIRESSS Dataset
Macrovascular (Group 1)	Hypertensive Disease (401-405) Acute Myocardial Infarction (410) Ischemic Heart Disease (410-414) Heart Failure (428) Stroke (430-438) Cardiovascular Disease (390-448)	401.9, 402.9, 403.9, 403.91, 405.9, 410.9, 410.93, 410.934, 412.9, 413.9, 413.96, 414, 414.8, 414.9, 415.1, 416, 416.9, 420, 421, 423.91, 423.92, 424, 424.01, 424.1, 424.13, 424.2, 425.4, 426, 426.002, 426.11, 426.13, 426.2, 426.3, 426.4, 426.53, 427.31, 427.5, 427.69, 427.81, 427.89 428, 428.1, 428.9 431.91, 433.1, 433.31, 434.9, 435.9, 436.91, 436.92, 437.8, 438.9 396.92, 397, 429.3, 429.9, 429.91, 440, 440.1, 440.2, 440.9, 441.4, 443.8, 443.9, 444.2, 447.1
Nephropathy (Group 2)		250.3, 581.8, 585, 585.1, 585.2, 585.3, 585.4, 585.5, 585.6, 585.9, 586, 586.91
Neuropathy (Group 3)		250.5, 358.1, 337.1, 357.2 , 713.5
Erectile Dysfunction (Group 4)		607.8
Retinopathy (Group 5)		250.4, 366.41, 362, 362.11, 362.3, 362.5, 362.8, 365.1, 365.6, 365.9, 366.4, 366.9, 369, 369.1, 369.2, 369.6
Foot Problems (Group 6)	Peripheral Circulatory Disorder Amputation	250.6, 443.8, 785, 785.4, 785.51, 785.59, 785.596 T96.11, T96.112, T96.12, T96.120, T96.141, T96.151

The vectors that were generated through application of the complications indexing scheme are given in Table V.8.

Table V.8 Patient Journey Based On Complications Of Diabetes

Patient ID	Complications Vector Pattern	Comment on Change
1 (visit 1) 1 (visit 2)	212010 312010	Progression to additional macrovascular and neuropathy problems
10660 (visit 1) 10660 (visit 2) 10660 (visit 3) 10660 (visit 4)	212010 212010 212010 212010	No change
14679 (visit 1) 14679 (visit 2)	000010 000010	No change
57991 (visit 1) 57991 (visit 2) 57991 (visit 3)	010010 110010 110010	Progression to macrovascular complication
23198 (visit 1) 23198 (visit 2) 23198 (visit 3)	310010 310010 210010	Removal of a macrovascular complication (supports pattern shown in Charlson Analysis, Table IV.15)
106039 (visit 1) 106039 (visit 2) 106039 (visit 3)	210010 210010 110010	Removal of a macrovascular complication
261372 (visit 1) 261372 (visit 2) 261372 (visit 3) 261372 (visit 4) 261372 (visit 5) 261372 (visit 6)	010010 010010 210010 210010 110010 110010	Progression to macrovascular complications with one macrovascular complication no longer coded on visit 5
361965 (visit 1)	411010	Multiple macrovascular coupled with nephropathy, neuropathy and retinopathy
434501 (visit 1) 434501 (visit 2)	111010 112010	Additional neuropathy complication
852165 (visit 1) 852165 (visit 2) 852165 (visit 3) 852165 (visit 4) 852165 (visit 5)	111010 111010 211010 111011 111011	Progression to foot problems
NS0093 (visit 1)	010000	Nephropathy complication

V.D Semantic Index For Case Visualization

The XML Topic Map standard was used to facilitate visualization of the relationships among patient cases, ICD-9 codes, Charlson Index Disease Groups and Complications of Diabetes Disease Groups. Through navigation of the Topic Map, the patient journey of individual cases was identified as their disease experience progressed from uncomplicated diabetes mellitus to diabetes mellitus complicated by organ damage.

Figure V.3 illustrates how implementation of this information in a Topic Map helped visualize the associations. The topic map zoomed in on a specific ICD-9 code, 428.1, standing for "INSUFFISANCE CARDIAQUE GAUCHE/OAP" in French and "Left heart failure" in English. It was associated with Charlson Index Disease Group 2, *Congestive Heart Failure,* and a subcategory, *Heart Failure,* of Complications of Diabetes Disease Group 1, *Macrovascular.*

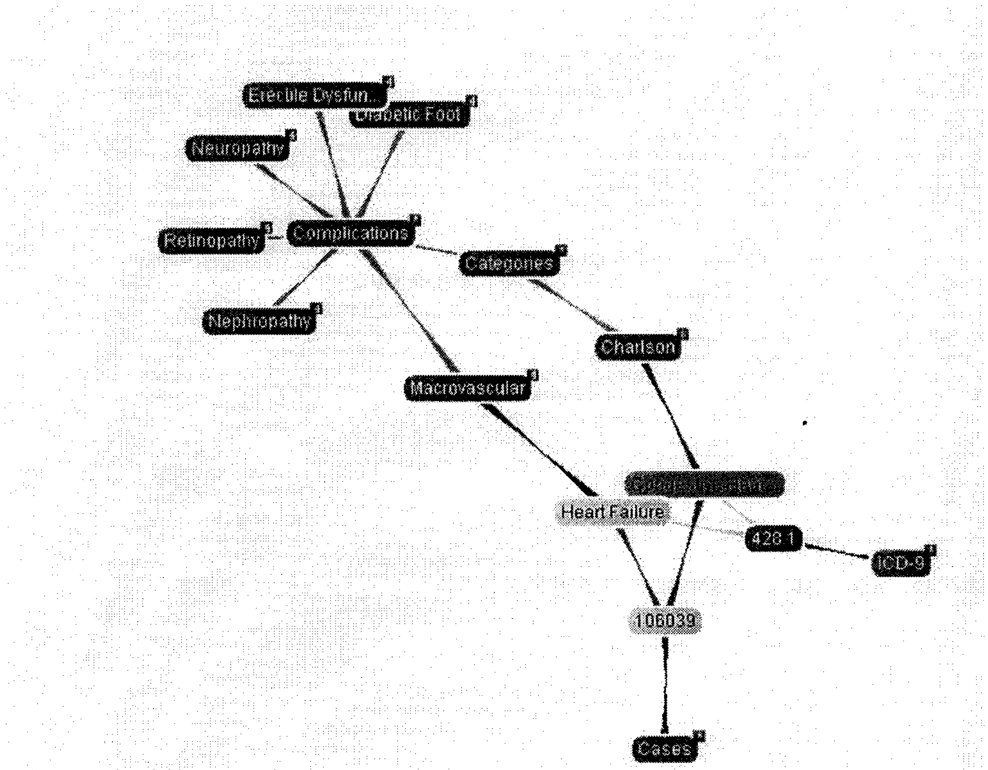

Figure V.3 Topic Map Showing Case, ICD-9 And Category Associations

Figure V.4 shows the topic types used in forming the Semantic Index for chronic kidney disease cases. The topic map introduced terms that were not in the text corpus, but rather were in the categorization rules for the semantic index.

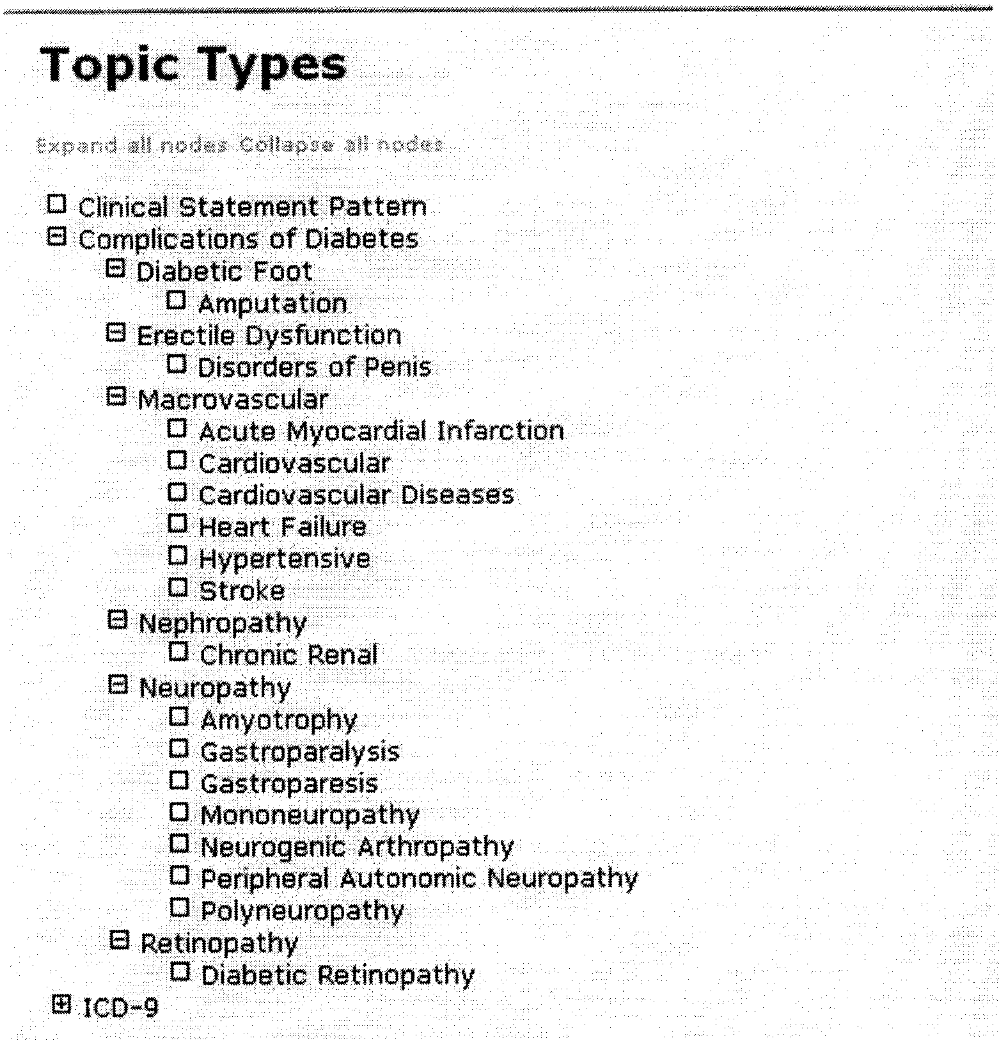

Figure V.4 Topic Types Used In Semantic Index

V.E Pragmatics Of Terminology In Software

The Clinical Document Repository was created from heterogeneous sources. It represented patient data that arose from the clinical activities in two jurisdictions, Halifax, Nova Scotia, and Sherbrooke, Quebec. The constrained terminology that was required to concurrently code the patient data at the time of data entry into a CDA-based discharge summary was described in Chapter IV. Study one's constrained terminology (877 concepts) was merged with study two's constrained terminology (595 unique ICD-9 codes and 158 unique CCP codes) to create the subject set of 1630 concepts for the Chronic Kidney Disease Topic Map.

Two data sources for the Clinical Document Repository were from Nova Scotia. These were the HL7 CDA documents produced using the HL7 Template for CKD Discharge Summary and the HL7 CDA documents produced from scanning pages of the patient chart into electronic form and adding metadata in the CDA Header. This metadata was described in Chapter IV.

Another data source for the Clinical Document Repository was Quebec patients' discharge records from the CIRESSS clinical data warehouse. The CIRESSS data was transformed into coded clinical documents using mySQL tables on the Dalhousie Faculty of Computer Science server[35]. This enabled populating a longitudinal electronic health record based on the HL7 Care Record Summary Template implemented as the PatientRx v.2 application on the HealthInfoRx™ server (204). Figure V.5 shows the original lab data for a CIRESSS extract.

R	S	T	U	V	W
ECLE_ZZ_DT	ECLE_ZZ_HR	TITRE_CHAMP	LIGNE_CHAN	TITRE_SOUS	VALEUR_CHAMP
1/30/2003	12:32	Rapport final	17		Note médicale
9/16/2002	14:16	Rapport final	2		Note médicale
9/16/2002	14:16	Rapport final	1		Note médicale
9/16/2002	14:16	Rapport final	0		Note médicale
9/16/2002	14:16	Date dictée	0		mar, 2002-09-17
9/16/2002	14:16	Rapport final	3		Note médicale
9/16/2002	14:16	Lu par - Radiologiste	0		Valeur encryptée
9/16/2002	14:16	No films	0		2
9/16/2002	14:16	Projections	0		PA et latéral
9/16/2002	14:16	Méthode transport	0		chaise roulante
9/16/2002	14:16	Raison	0		Note médicale
9/16/2002	14:16	No expositions	0		2
9/16/2002	14:16	Examen fait à	0		
9/16/2002	14:16	Rapport final	4		Note médicale
9/16/2002	14:16	Rapport final	6		Note médicale
9/16/2002	14:16	Lu par - Radiologiste	0		Valeur encryptée
9/16/2002	14:16	No expositions	0		2
9/16/2002	14:16	No films	0		2
9/16/2002	14:16	Projections	0		PA et latéral
9/16/2002	14:16	Rapport final	5		Note médicale
9/16/2002	14:16	Méthode transport	0		chaise roulante
9/16/2002	14:16	Examen fait à	0		

Figure V.5 CIRESSS Extract With Lab Data

[35] http://www.cs.dal.ca/studentservices/faq/tutorials/web_sites/connect_mysql.php

The CIRESSS lab data was cleaned and mapped to the labels used in Nova Scotia for lab test names and results (Figure V.6). This facilitated comparison of patient data from two jurisdictions.

	A	B	C	D	E	F	G	H
1	Rxid	encounter	labtestdate	testname	testcode	labtestdescription	testresult	unit
2	Q06039	Q06039-1	4/9/2001	Phosphatase alcaline	AP	Alkaline Phosphatase	177 g	U/L
3	Q06039	Q06039-1	4/9/2001	AST	AST	Aspartate Aminotransferase	32	U/L
4	Q06039	Q06039-1	4/9/2001	Baso ab	BASO	Basophils	0	%
5	Q06039	Q06039-1	4/9/2001	Baso si	BASO ABS	Basophils, Absolute	0.005	%
6	Q06039	Q06039-1	4/9/2001	CK	CKMB	Creatine Kinase MB Isoenzy	43	ug/L
7	Q06039	Q06039-1	4/9/2001	Eosi ab	EOS	Eosinophils	0.4	%
8	Q06039	Q06039-1	4/9/2001	Eosi si	EOS ABS	Eosinophils, Absolute	0.042	%
9	Q06039	Q06039-1	4/9/2001	Hte	HCT	Hematocrit	0.401	
10	Q06039	Q06039-1	4/9/2001	Hb g/L	HGB	Hemoglobin	131	g/L
11	Q06039	Q06039-1	4/9/2001	Potassium	K	Potassium	4.2	mmol/L
12	Q06039	Q06039-1	4/9/2001	Lymp si	LYMPH	Lymphocytes	0.203	%
13	Q06039	Q06039-1	4/9/2001	Lymp ab	LYMPH ABS	Lymphocytes, Absolute	1.8	%
14	Q06039	Q06039-1	4/9/2001	TGMH Pg	MCH	Mean Corpuscular Hemoglob	31.9	pg
15	Q06039	Q06039-1	4/9/2001	CCMH g/L	MCHC	Mean Corpuscular Hemoglob	328	g/L
16	Q06039	Q06039-1	4/9/2001	VGM fL	MCV	Mean Corpuscular Volume	97.1	fL
17	Q06039	Q06039-1	4/9/2001	Mono ab	MONO	Monocytes	0.5	%
18	Q06039	Q06039-1	4/9/2001	Mono si	MONO ABS	Monocytes, Absolute	0.061	%
19	Q06039	Q06039-1	4/9/2001	VPM fL	MPV	Mean Platelet Volume	7.8	fL
20	Q06039	Q06039-1	4/9/2001	Sodium	NA	Sodium	135	mmol/L
21	Q06039	Q06039-1	4/9/2001	Plt10e9L	PLT	Platelet Count	317	10E9/L

Figure V.6 Normalization To English Lab Test Descriptions

The Quebec patients' data from the CIRESSS system was entered into HL7 CDA documents using the HL7 Care Record Summary Template. The XML Style Language (XSL) was used to populate the longitudinal record from lab data stored in mySQL tables and to render the information in a human-readable form for display using the Internet Explorer web browser.

The cross-mappings between nosology systems were provided with licenced copies of SNOMED CT and UMLS. The Canadian Institute for Health Information (CIHI) provided the CORR to ICD-10-CA mapping. The mappings among diagnoses coding schemes were stored in database records maintained by mySQL software. Figure V.7 shows the diagnoses coded for Quebec patient 106039.

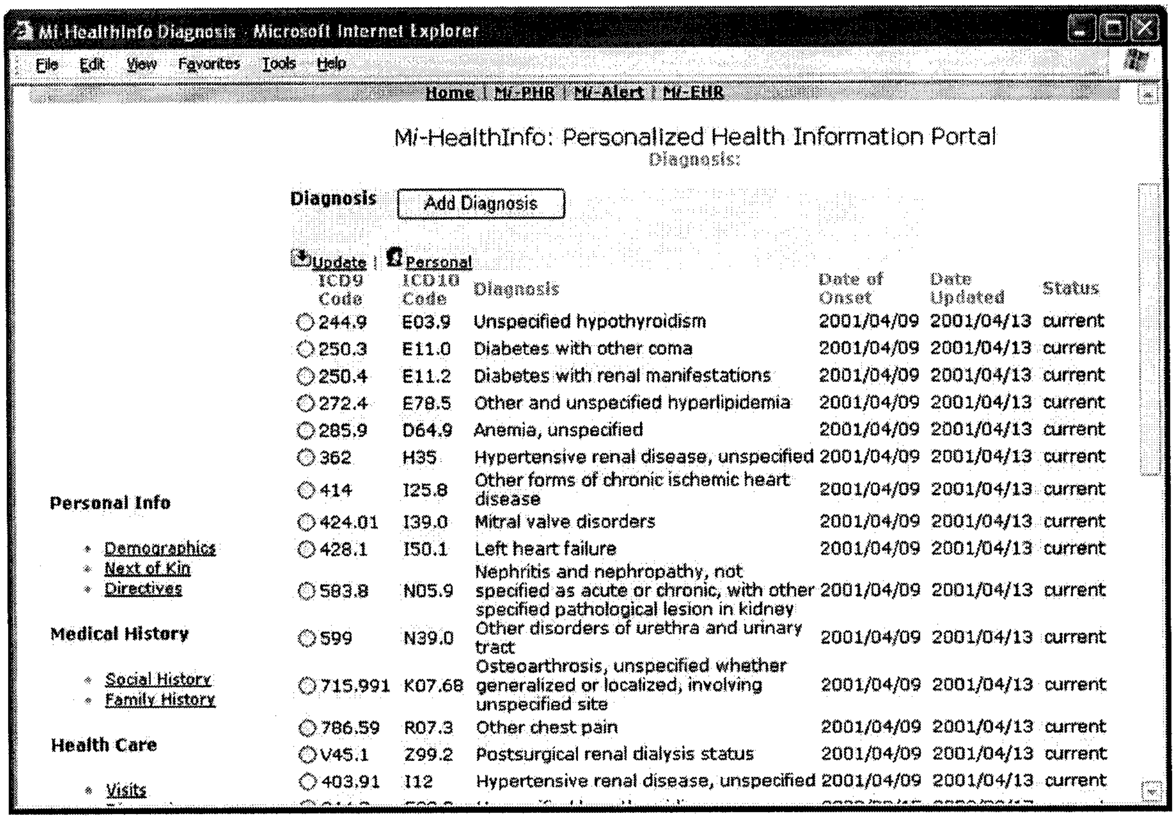

Figure V.7 HL7 Care Record Summary Version Of CIRESSS Patient Data

The diagnoses entries, lab results, vital signs and medication events in the HL7 CDA entries for CKD Discharge Summaries were normalized using mySQL and rendered as Clinical Statement Patterns using XSL. This provided a common look to Clinical Document Repository entries from the two jurisdictions, Halifax, Nova Scotia, and Sherbrooke, Quebec.

All narrative entries in discharge summaries were processed to discover codable concepts for the subjects analysis. A combination of automated and manual methods was used. These included a SnoCode® tool to automatically map text to SNOMED 3.5, ICD-9 and ICD-10 and a MetaMap Transfer (MMTx) program to automatically map text to UMLS concepts (201). MMTx allowed us to constrain mapped concepts to those terminology boundary objects, such as SNOMED CT, selected for the boundary infostructure.

V.F Conceptual Model For Chronic Kidney Disease Topic Map

The Chronic Kidney Disease Topic Map was conceived as three layers (Figure V.8). The ontology process identified the subjects' layer as the constrained terminology used to generate the HL7 CDA entries for the Clinical Document Repository. The terminology was represented in one or more boundary objects. The structures' layer arose from nosological, lexical, semantic and HL7 structures used for identification of similar cases. The context layer arose from the user perspective, which was the five user groups in the CHAMP Community of Learners model.

This research produced a testbed based on the conceptual model for the Chronic Kidney Disease Topic Map. Version Two

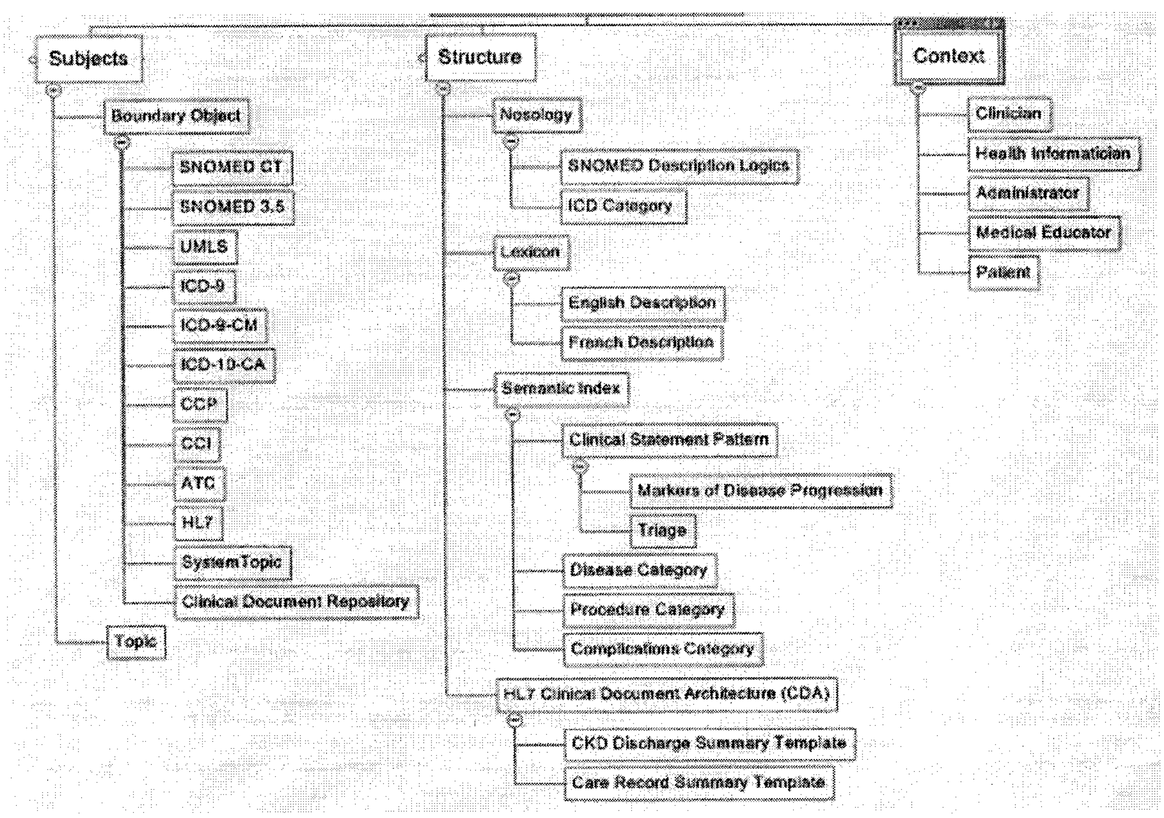

Figure V.8 Chronic Kidney Disease Topic Map Version 2

Chapter VI: Study Three: Patient Portal Webpages

This study was conducted to test the constrained terminology and usefulness and usability hypotheses. The ontology process was applied to identify the constrained terminology, categorize it using boundary objects and interpret it for multiple user contexts.

The items in the Inflammatory Bowel Disease patient portal were semantically indexed and put into a Patient Information Repository. The semantic knowledge permitted inferences to be made and the pragmatic use was to answer pre-constructed questions by compiling information across subject references. This reorganization was sought because greater than 50% of recruited patients had answered "don't know" to a set of items in a knowledge quiz. The site was evaluated to determine whether or not it had contained content to answer all items in the knowledge quiz. The method employed for this investigation was Socratic Completeness.

VI.A Study Three Methods

The title of this study was *HealthInfoRx™: Lifelong Learning for Chronic Disease Patients and Their Caregivers.* The author, John L. Ginn and David Zitner, Medical Informatics, Dalhousie University, were co-investigators for the original study. See Appendix E for the form used for Informed Patient Consent for the original study that produced the texts that were analyzed for this research. Other information about this study was published in (31,32). This research used the output of the original study as input to a boundary infostructure analysis.

VI.A.1 HealthInfoRx Study Results

Patients were randomly selected by a computer program to receive a letter of invitation to take part in the research study that provided findings for analysis in this research. Patients could take part in the research study if they had access to the Internet and were a patient with the Specialty IBD Clinic in Halifax, NS. The research study was a six-month pilot study of a web portal that provided secure communications, education, and support for self-management by Inflammatory Bowel Disease (IBD) patients. The study evaluated the impact of this intervention on quality of life using the SF-36 and the Inflammatory Bowel Disease

Questionnaire (IBDQ) pre and post. Patients' learning outcomes were evaluated using the Crohn's and Colitis Knowledge Score (CCKNOW) test instrument pre and post.

Seventy-six patients (26 male, 50 female) were enrolled from the IBD Clinic in Nova Scotia; 2 withdrew; 57 accessed the site; 49 completed the health status instruments, Short Form 36 (SF-36) and Inflammatory Bowel Disease Questionnaire (IBDQ); and 47 completed the CCKNOW pre and post.

VI.A.2 Change In Knowledge Of IBD As Measured By CCKNOW

There were forty-seven patients who completed the CCKNOW pre and post. There was moderate improvement in overall scores, 12.61 (CI 11.32-13.90) pre and 13.17 (CI 11.85-14.49) post, approaching statistical significance (*P<0.07*).

The change in CCKNOW scores were categorized into three groups: most improved (N=6), improved or no change (N=10), and worsened (N=8). The item results are given in Table IV.1 using question numbering from Eaden [4].

Table VI.1 Learning Outcomes Measured By CCKNOW

Question	Pre (%)	Post (%)	Change
q2	100.0	100.0	0.0
q3	56.3	60.4	4.2
q4	37.5	47.9	10.4
q6	100.0	95.8	-4.2
q7	68.8	64.6	-4.2
q9	68.8	64.6	-4.2
q10	70.8	75.0	4.2
q11	58.3	56.3	-2.1
q12	10.4	6.3	-4.2
q13	39.6	33.3	-6.3
q15	72.9	89.6	16.7
q16	52.1	70.8	18.8
q17	39.6	45.8	6.3
q18	22.9	33.3	10.4
q20	47.9	50.0	2.1
q22	6.3	18.8	12.5
q23	70.8	58.3	-12.5
q24	50.0	52.1	2.1

Question	Pre (%)	Post (%)	Change
q25	27.1	43.8	16.7
q26	60.4	68.8	8.3
q27	16.7	16.7	0.0
q28	47.9	50.0	2.1
q29	83.3	62.5	-20.8
q30	50.0	52.1	2.1

VI.A.3 Patient Portal Usage

Fifty-seven patient accessed the portal. They logged into the portal 893 times. Usage ranged from 96% for FAQs to 28% for private messaging. Of those who posted a question not found on the FAQs, most (91%) were comfortable or fairly comfortable doing this.

VI.B Boundary Infostructure Methods

The IBD patient portal was evaluated for its ability to deliver the correct answers to a knowledge quiz. This was done by determining whether the website supported navigation from a question in a knowledge quiz to content that answered the question. The completeness method used semantic connections between concepts to focus its search for useful information. The semantics accurately reflected the potential reasoning ability if the correct conclusion could be found based on the right series of questions (32). This is known as the Socratic Completeness method (29).

The process was:

1. Step 1: Transform the constrained terminology into an ontological representation in the form of a topic map.
2. Step 2: Store items from the IBD Patient Portal as topic maps in the Patient Information Repository.
3. Step 3: Represent each item in the knowledge quiz as a topic map query.
4. Step 4: Use the Socratic Completeness method to evaluate semantic interoperability among items in the Patient Information Repository for the task of answering questions in a knowledge quiz.

The aim was to infer facts from implicit knowledge in the ontology. Socrates' method was to question another "to elicit a clear expression of a truth supposed to be implicitly known by all rational beings" (190).

Items in HealthInfoRx™, the web portal for IBD patients, were analyzed for content coverage and completeness. The portal development was dynamic and ultimately composed of 93 Frequently Asked Questions (FAQ), 5 pamphlets, 13 learning modules, a discussion group with 32 discussion threads, 10 Cochrane plain language summaries, a glossary with 398 items, the SF-36, the IBDQ, the CCKNOW test and a continuing medical education module.

VI.B.1 Constrained Terminology

The automatic indexing of the entire IBD patient portal using MMTx found 29,373 UMLS codes, of which 3,035 were unique.

For the concordance analysis, manual indexers sought UMLS codes for 1361 indexing terms in 93 FAQs and were successful 782 times (57%). They sought UMLS codes for 398 glossary terms and were successful 348 times (87%). The automatic indexing of the FAQs using MMTx found 5302 UMLS codes, of which 1170 were unique. The automatic indexing of the 398 glossary terms generated 418 UMLS codes.

A comparison of manual and automatic indexing identified 107 UMLS codes in the manual indexing set that were not in the MMTx-generated set. This led us to a bounded set of 3,142 concepts for the topic map used for our completeness evaluation. Of the bounded set, 3,035 concepts (96.6%) were drawn from SNOMED CT. The 3,142 concepts are indexing terms which are coupled with terminological knowledge from ULMS and SNOMED CT to form a Semantic Index for a webpage. The Semantic Index enables linkages between webpages based on inferences supported by SNOMED CT ontological structure.

The poorest performance by patients on the CCKNOW pre-test was q22 where only three patients answered correctly.

> *Male patients who take sulphasalazine:*
>
> *a) Have reduced fertility levels that are reversible*

b) Have reduced fertility levels that are not reversible

c) The drug does not have any effect on male fertility

d) Don't know

The item asked about the possible reduction of fertility in male patients who took sulphasalazine. In the post test, five patients changed their incorrect response of "don't know" to the correct response. This led to an improvement in the performance of that test item. However, it still showed that 65% of patients responded "don't know" to this question post test.

The CCKNOW had three questions (q16, q17, q22) on sulphasalazine, a medication with a British spelling as used in CCKNOW and an American spelling, sulfasalazine, as used in the IBD patient portal. The CLUE Browser for SNOMED CT supported two languages, US English and UK English. When UK English was chosen, you were able to view a concept in both language versions, since US English was always used for the fully specified name that linked the concept with its semantic class.

Figure VI.1 gives the CLUE Browser screen for ConceptID 45844004, with *sulfasalazine (product)* as the fully specified name in US English and *sulphasalazine* as the preferred spelling in UK English. A terminological resource can help solve the lexical variation issue, since a method was sought to resolve lexical variations that arose from language versions.

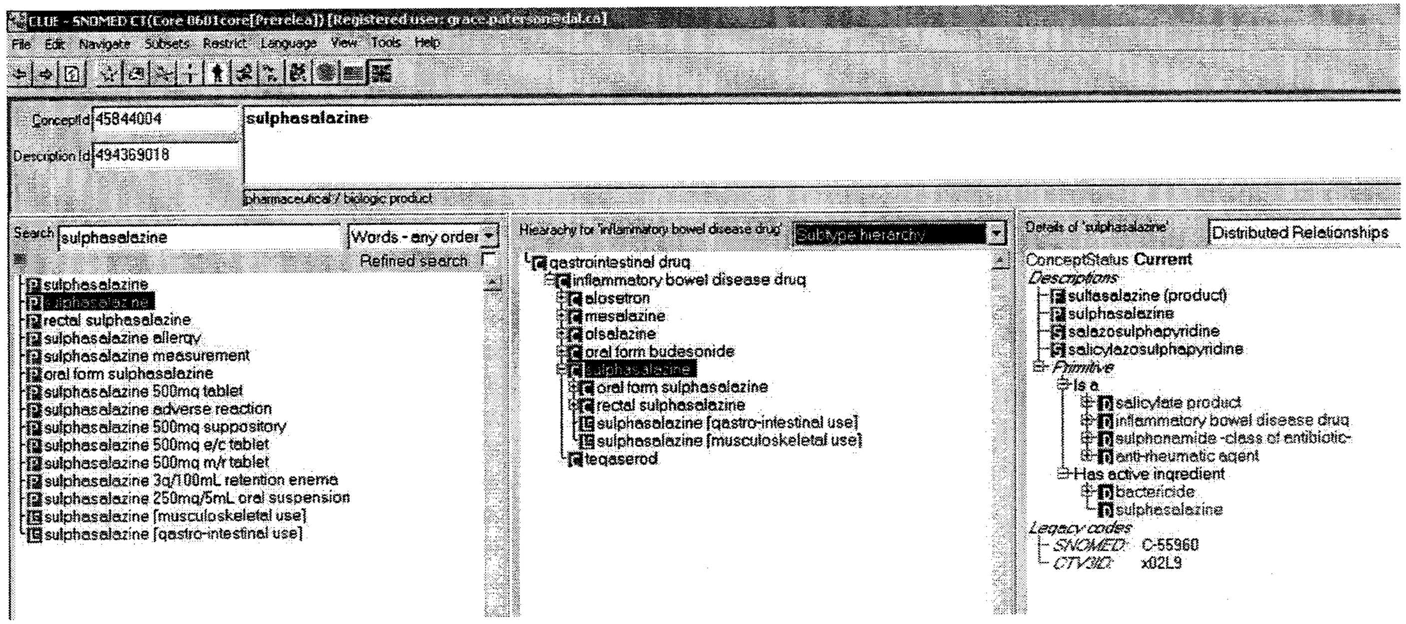

Figure VI.1 UK English And US English Representations In SNOMED CT

A search for the term on the patient portal returned one result from the glossary, showing an association between 5-ASA, sulfasalazine, and mesalamine. A search for the term "5-ASA" returned 5 FAQs. There were two entries in Cochrane summaries for sulfasalazine that said male infertility occurs but there was no discussion of reversibility and three entries in pamphlets which stated a side effect was a reduced sperm count in men that returned to normal when the drug was stopped. The patients needed to be able to infer that reduced fertility levels and reduced sperm count had an equivalent meaning. There was an entry in the discussion forum that was misspelled (sulfasaline) saying patient was on medication but no discussion of male infertility.

The indexing of the IBD Patient Portal was done using an IBD Factors form (Figure VI.2). This showed that the controlled vocabulary included 5-ASA but not sulfasalazine for site indexing. The IBD Patient Portal contents were indexed by topics in the IBD Factors form.

Question Topics

Diagnosis and Lifecycle		
Crohn's Disease	Ulcerative Colitis	
Population and Incidence		
Risk Factors	Family History/Genetics	Disease Activity and Remission
Anatomy		
Immune System	Reproductive System	Skeletal System (bones)
Digestive System	Nervous System	
Full Gastrointestinal Tract		
Upper Gastrointestinal Tract		
Stomach		
Small Bowel/Small Intestine		
Large Bowel/Small Intestine		
Living with IBD		
Pediatrics	Pregnancy	Lifestyle (exercise, smoking)
Psychological and coping	Quality of life (trade off between comfort, function & treatment)	
Treatments		
Drugs	Surgery	Other: alternative medicine
Corticosteroids		
Immunosuppressants		
Pain medication		
5-ASA		
Antibiotics		
Bisphosphonates		
Anti-TNF Inhibitor		
Non-Steroidal Anti-Inflammatory		

Figure VI.2 IBD Factors Indexing For IBD Patient Portal

VI.B.2 HL7 Structured Product Labeling

HL7 Structured Product Labeling (SPL) is a specification for drug inserts. It was developed by the HL7 Structured Documents Technical Committee and approved by the Food and Drug Administration[36]. The human-readable and computer-readable (XML) files were stored on a

[36] http://www.fda.gov/cder/meeting/SPL.htm

National Library of Medicine website[37]. These XML files were employed to help implement the Socratic Completeness method, whereby a question could be answered by navigating the topic map using access-limited logic. The topic map showing the connection between a medication side effect and the medication is shown in Figure VI.3.

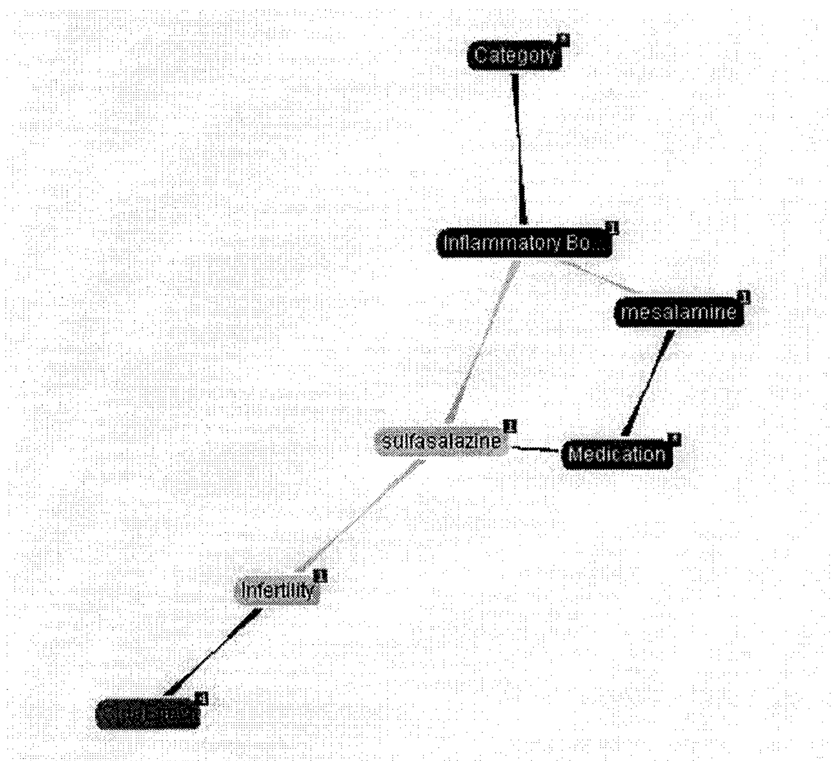

Figure VI.3 Topic Map For Inflammatory Bowel Disease Drug

VI.C Content In IBD Patient Portal Versus Knowledge Test

The patients expressed what they wanted to know about through FAQs. A comparison of content sought versus content examined using CCKNOW indicated differences. It suggested that this may have impacted patients' performance with CCKNOW.

For the completeness analysis, inference rules were generated through question analysis. The process confirmed that information to answer all CCKNOW questions could be inferred from content on the IBD patient portal with pragmatic enhancement from eHealth resources. These

[37] http://dailymed.nlm.nih.gov/dailymed/about.cfm

included the ontological knowledge from terminology systems and the Structured Product Labeling information for drug inserts. These resources were boundary objects.

VI.D Conceptual Model For The Inflammatory Bowel Disease Topic Map

This research produced a testbed based on the conceptual model for the Inflammatory Bowel Disease Topic Map (Figure VI.4).

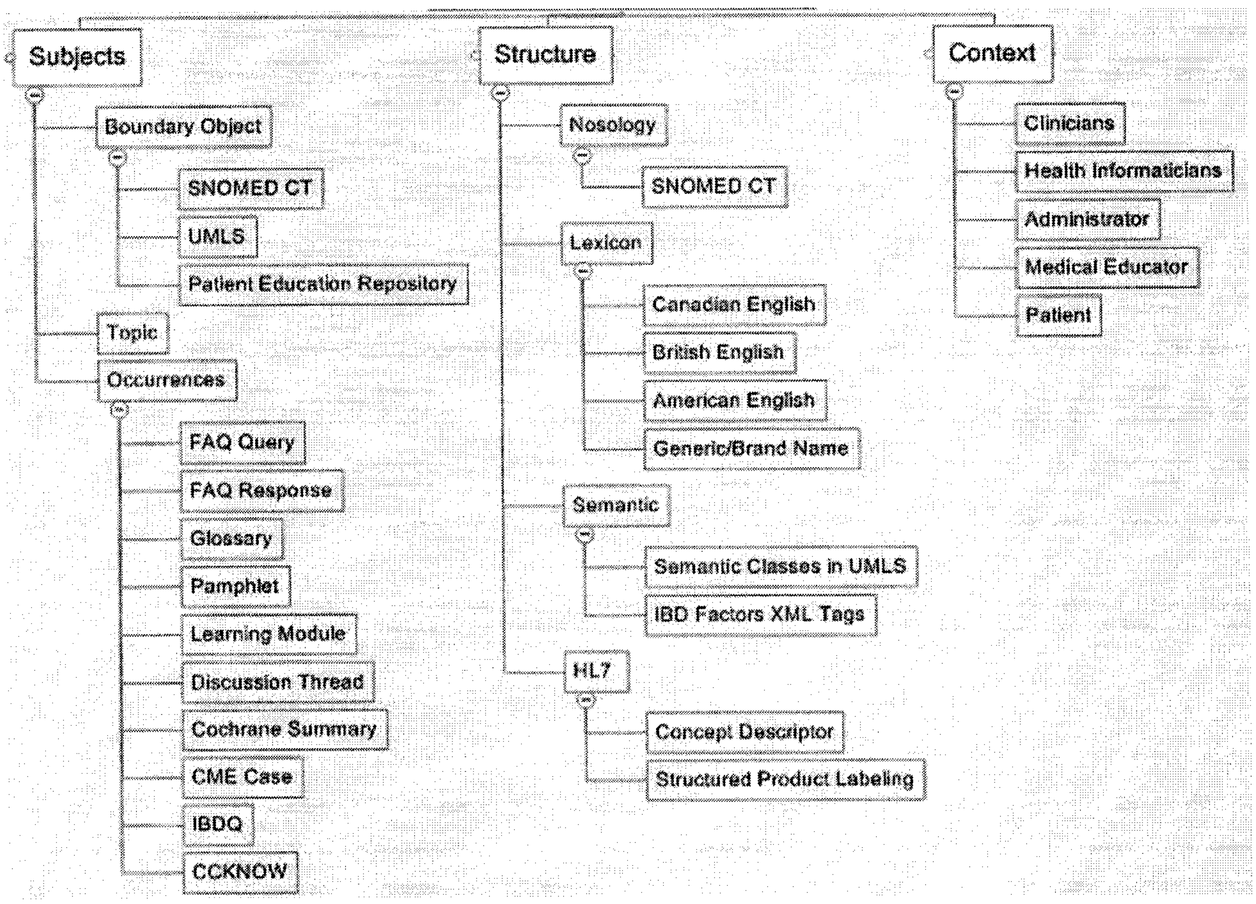

Figure VI.4 Inflammatory Bowel Disease Topic Map

Chapter VII: Evaluation For CHAMP Community Of Learners

The members of the CHAMP Community of Learners are Clinicians, Health Informaticians, Administrators, Medical Educators and Patients. The hypotheses categorized as clinical pragmatics were applied for the evaluation of the boundary infostructure for the CHAMP members. These hypotheses were:

1. *Data Quality Improvement:* The quality of Discharge Summaries for chronic kidney disease patients can be improved by using a template to prompt medical residents to enter relevant data when documenting care.
2. *Clinical Pragmatics:* The boundary infostructure supports practical data entry, browsing and retrieval for clinical tasks.
3. *Usefulness and Usability*: Patient data provides a repository of activities and results that can be used to generate new medical knowledge for integration with knowledge from external sources and for prompting clinicians at the time of care.

VII.A Data Quality Improvement And Impact On Learners

The CanMeds 2005 physician competency framework motto was *"Better Standards - Better Physicians - Better Care"* (142). Equipping clinicians with health informatics skills and knowledge is part of the challenge for achieving better physicians and better care.

Improvement in data quality was indicated through use of a template to prompt trainees for data elements considered pertinent for chronic disease management. XML technologies could be applied to transform the electronic discharge summary into forms needed by other of the CHAMP Community of Learners. This research confirmed that normalization of the patient data using HL7 Clinical Statements enabled transformation for the following purposes:

1. From electronic discharge summary to encounter entry in the patient's longitudinal health record based on the HL7 Care Record Summary Template

2. From electronic discharge summary to Initial Registration form for the Canadian Organ Replacement Register for administrators

3. Facilitating migration of data from the CIRESSS discharge records and the discharge summary to repositories based on the Western Health Information Collaborative Chronic Disease Management standard

4. Patient data sent with referrals from family physician to specialist, to facilitate triage by clinician and to facilitate booking appointments by administrators

5. Semantic indexing of patient cases to provide more case examples for medical educators

Learning at the boundary between the health informatics and clinician communities of practice was demonstrated through development of the HL7 Template.

VII.B Clinical Pragmatics And Impact On Learners

Clinical pragmatics is practical data entry, presentation and retrieval for clinical tasks, and the behaviour of terminology in software. The research was not able to match the time it took to produce a discharge summary through dictation and transcription with the time it took to produce one using the HL7 Template. This was a serious flaw that impacted on study recruitment. The standardized instrument of the same patient chart was problematic because the participants had to generate the patient story from handwritten and illegible progress notes.

VII.C Usefulness And Usability And Impact On Learners

There were questions that were posed to the data that enabled visualization of the answers. First of all, there was identification of clinical pragmatic patterns in text that demonstrated multiple ways to convey the same information. As an example, Table VII.1 shows the multiple ways that the reason for a medication was classified by boundary objects. This contrasts with the words used by the clinicians to state the reasons for a medication. The clinicians showed a tendency to use shortened forms that perhaps do not have a standard meaning. For example, "Fe-def anemia" could be interpreted as iron deficiency anemia, but that might be expecting a lot of one's readers. It appeared that the meaning was sufficiently similar across the same community of practice to reflect common knowledge. The classification information provided by the classification systems was attributed to the health informaticians community of practice.

Table VII.1 Reasons for Medication Versus ATC And SNOMED CT Classification

Medication	ATC Classification	SNOMED CT Classification	Study Participants Reason for Use 58797 and 88065
Lasix	HIGH-CELING DIURETICS C03CA SULFONAMIDES, PLAIN	sulfonamide diuretic	Diuretic | HTN
Norvasc	SELECTIVE CALCIUM CHANNEL BLOCKERS WITH MAINLY VASCULAR EFFECTS C08CA DIHYDROPYRIDINE DERIVATIVES	calcium channel blocking agent	anti-hypertensive | HTN
Lipitor	LIPID MODIFYING AGENTS, PLAIN C10AA HMG-CoA REDUCTASE INHIBITORS	HMG-CoA reductase inhibitor	Dyslipidemia | hyperlipidemia
Allopurinol	ANTIGOUT PREPARATIONS M04AA PREPARATIONS INHIBITING URIC ACID PRODUCTION	xanthine oxidase inhibitor	Gout | Gout
Glyburide	SULFONAMIDES, UREA DERIVATIVES	second generation sulfonylurea	anti-hyperglycemic | Diabetes
Acebutolol	BETA BLOCKING AGENTS, SELECTIVE	Beta 1 blocking agent	anti-hypertensive | HTN
Cardizem	BENZOTHIAZEPINE DERIVATIVES	calcium channel blocking agent	anti-hypertensive | HTN
FeSO4	IRON IN COMBINATION WITH FOLIC ACID	oral iron agent	Fe-def anemia | anemia

The Clinical Document Repository provided a store of information that could be mined for pertinent and superfluous activities. As an example, we could determine how many patients had anemia by considering their lab results. The anemia case definition from the World Health Organization's Global Burden of Disease[38] study was used to categorize a patient case as anemic or not. Then, the HL7 Template for Chronic Kidney Disease Discharge Summary was used to determine the appropriate lab workup for a patient with hemoglobin level that was classified as either normal, mild, moderate or severe. This workup was special hematology tests for ferritin and transferring saturation (% saturation). If those lab results were recorded for a patient with non-normal hemoglobin, then the case was flagged as *anemia pertinent.* If those lab results were not recorded, then the case was flagged as *anemia not pertinent.* Those patients who have no anemia were not expected to have the special hematology tests, so are flagged as *anemia pertinent* if the results were omitted. The HL7 Clinical Statement model provided a

[38] http://www.who.int/healthinfo/statistics/gbdestimatescasedefinitions.pdf

common way to express lab results, so this facilitated clinical pragmatics. Figure VII.1 is a visualization showing how a topic map links from the clinical pragmatics example to the pertinence indicator.

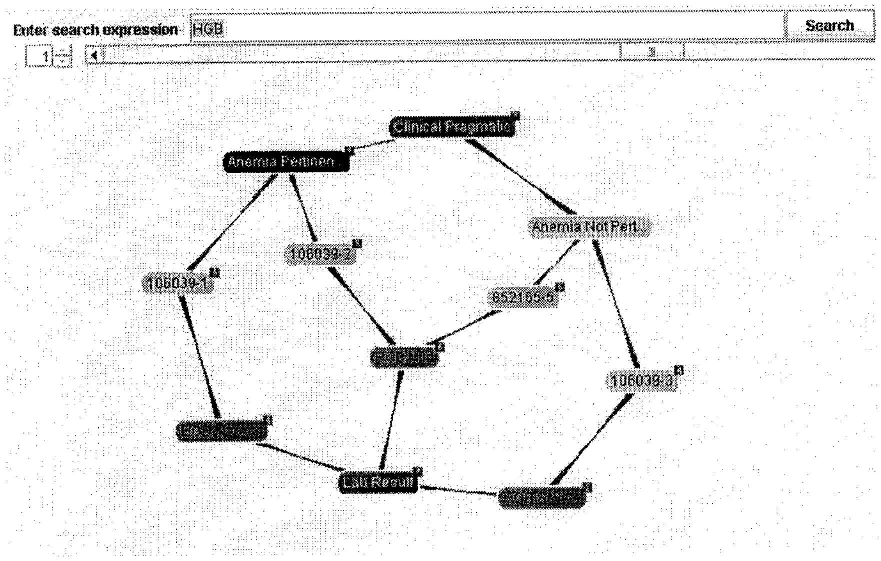

Figure VII.1 Clinical Pragmatics and Pertinent Activities

HL7 Clinical Statements expressed the specific patient's data in a manner that matched with the Department of Medicine's Triage system. By ensuring that the electronic health information that was needed was expressed the same way for all patients, we could achieve semantic interoperability among the community-based physicians making referrals, and the clinicians acting on the referrals. Administrators, such as the booking clerks, act on the same information in scheduling appointments.

To leverage electronic clinical documents as an alternative source for cases in a case-based reasoning system a method was defined for case indexing. The semantic index for each patient case was evaluated for its ability to express clinical pragmatic patterns that associated activities with results.

Chapter VIII: Evaluation Of Topic Maps

The topic map was proposed as a solution for the semantic interoperability problem. The three hypotheses associated with semantic interoperability were:

1. *Constrained Terminology*: Semantic interoperability among electronic health resources can be achieved using a range of UMLS source vocabularies that provide domain coverage.
2. *Commensurability of Different Classifications:* We can make commensurable the different classifications used by members of the CHAMP Community of Learners by grounding the symbols used for encoding clinical events in nosology systems (ICD and SNOMED), thesauri and eHealth resource examples.
3. *Common Ground:* Topic maps can function as the infostructure "glue" to mediate learning at the boundary between and among different communities of practice.

For the semantic interoperability dimension, it was difficult to match the term for a diagnosis used by administrators with the one used by clinicians. This was similar to the experience of Pereira et al. (202). The coding rules required manual intervention in their application.

Health record coders hired by hospital administrators assigned an ICD-9 code to a diagnosis in Quebec and an ICD-10-CA code to a diagnosis in Nova Scotia. CIHI's Coding Query database was a tool used by administrators to help them interpret clinical documentation for the purpose of classification and coding to ICD-10-CA. There was often a mismatch between the clinician's words and the expression in ICD-10-CA. As an example, if a clinician stated, "Chronic Renal Failure due to Diabetes", the health record coder would be advised to enter a dagger (†) and an asterisk (*) code. These were: E11.22†, "Type 2 Diabetes Mellitus with end-stage renal disease (ESRD)" and N08.3* "Glomerular disorders in diabetes mellitus (E10-E14† with common fourth character .2)" (157). The dagger and asterisk system was for dual classification for certain diagnostic statements.

The Topic Map addressed the issue of term mismatch by focusing on the code and linking it to its subject representation. The subject representation included the expression in English and French languages, the UMLS CUI and term expression, and the ICD-9 code mapping to ICD-

9-CM and ICD-10-CA. The structure layer provided the assignment of subject entries to vectors used in the Semantic Index. These vectors are the Charlson Index disease groups, Complications of Diabetes and clinical statement patterns for lab results and medication events. One useful function was the ability to determine if clinical activity was pertinent. There are potential savings in human resources and clinical resources if superfluous activities could be determined and eliminated, without impacting patient health outcomes. The lab results facilitated identification of risk for a disease (190).

Through navigation of the Topic Map, a member of the CHAMP Community of Learners could gain an understanding of the different classification used by the other members and through comparison of the differences reach a shared ground. Many of the clinicians recruited for the Transcription versus Template study were eager to utilize electronic discharge summaries as a tool for improving chronic disease management. Similarly, many patients are destined to have an electronic patient health record, and the boundary infostructure demonstrated an ability to generate the information that patients need.

The boundary infostructure helped make commensurable the different classification systems used by clinicians, health informaticians, administrators, medical educators and patients. The UMLS was able to function as a switching language through its lexical properties as a metathesaurus formed from multiple source vocabularies, including ICD-9, ICD-10-CA, SNOMED CT and SNOMED 3.5.

A set of common patterns for asserting a lab value as an observation were available from HL7 Version 3 Standard[39], "*Using SNOMED CT in HL7 Version 3; Implementation Guide, Release 1.2*".

The ontology process used the real entities of discharge summaries, discharge records from a clinical data warehouse and texts from a patient portal to identify the subject matter. The categorization of subjects by structures in nosology, lexical, semantic and HL7 resources helped with comparison. The potential for topic maps to achieve a shared ground was demonstrated in this research.

[39] http://www.hl7.org/v3ballot/html/welcome/environment/index.htm Last Published: 03/20/2007 10:21 AM

Chapter IX: Conclusions

The essential problem was to manage the migration from using paper to using electronic records and to address issues that related to communication and interoperability in healthcare. These issues were grouped into two problems. The clinical pragmatics problem addressed practical data entry, presentation and retrieval for clinical tasks, and the behaviour of terminology in software (27). The semantic interoperability problem addressed shared meaning among five communities of practice in the CHAMP Community of Learners model: clincians, health informaticians, administrators, medical educators and patients. The paradigm shift from paper to electronic records impacted learning because it changed the way information was stored. The current health infostructure is based on disease classification which has political and philosophical implications (190). The adoption of a common nomenclature is considered part of the correction that would facilitate a paradigm shift from disease management to risk management. This would also facilitate the capture of health status along the dimensions of comfort, function and likelihood of dying (152).

There was evidence that coding data to ontologically-based terminology systems, such as SNOMED CT and UMLS, rather than the ICD categorization scheme would have an impact on the theoretical constructions that are placed on patient data (191). It impacted the time efficiency of physicians and nurses (49). If we moved the diagnostic coding closer to the source of healthcare activity, that is, the clinician, it would impact the assignment of case mix groups and reimbursement schemes as was shown with the introduction of ICD-10-CA (116). The ICD nosology used in the current infostruction for reimbursement is a disease classification, whereas the SNOMED nosology recommended for electronic records is a nomenclature. The Primary Renal Diagnosis codes currently used by Nova Scotian clinicians for scheduling appointments are a SNOMED subset. Quebec's health informaticians facilitate information retrieval from their hospital data warehouse through SNOMED encoding of structured data and narrative reports (158).

There is evidence of a shift to SNOMED CT as the common language for electronic records. The Problem List Subset of SNOMED is used by the Structured Product Labeling format for medications, and these are available through *DailyMed,* an online health information clearinghouse sponsored by the National Library of Medicine. Medications are often given to prevent a health outcome, such as the prevention of end stage renal disease through early screening and intervention. An ICD-based health infostructure does not allow such health outcomes to be captured. Such eHealth resources play a role in learning because they provide members of the CHAMP Community of Learners with associations between a problem and a therapy, and the possible side effects of a therapy.

The thesis investigated the question: How might a boundary infostructure be created that would bridge communities of practice that have perspectival differences; and how might this infostructure produce electronic health resources that are more semantically interoperable than those created by current infostructures?

The major literature source for the boundary objects theoretical foundation was publications by Susan Leigh Star (33-35,52,55,80,176,192) and her co-authors, James Griesemer (34) and Geoffrey Bowker (35,80,176,192). The notion of the community of practice and learning that occurs at the boundary between and among communities of practice came from Etienne Wenger's publications (23,108,109). The notion of making commensurable the different classifications used for interpretation by communities of practice came from Thomas Kuhn's philosophical essay (191). The notion of conversational maxims to analyze the quality of electronic discharge summaries came from the pragmatic philosopher, Paul Grice (24).

The process involved creating boundary objects as a tool for bridging the five communities of practice in the CHAMP Community of Learners framework. These communities are clinicians, health informaticians, administrators, medical educators and patients. Two boundary infostructures for chronic diseases were created, one for Chronic Kidney Disease and the other for Inflammatory Bowel Disease.

IX.A Evaluation Of Boundary Infostructure For Chronic Kidney Disease

The boundary infostructure for chronic kidney disease was evaluated against the major goals of a working group on evaluation and classification of chronic kidney disease. These were: "*To* *adopt a common evaluation and classification of chronic kidney disease. To facilitate the adoption of a common nomenclature worldwide"* (190).

The created boundary objects in the Chronic Kidney Disease infostructure were:

1. HL7 Template for Chronic Kidney Disease Discharge Summary
2. Semantic Index for Chronic Kidney Disease Cases
3. Clinical Document Repository
4. Chronic Kidney Disease Topic Map

These were evaluated for their contribution to a solution that meets the above goals and answers the research question. This was addressed along two dimensions: clinical pragmatics and semantic interoperability. The components of the clinical pragmatics dimension are practical data entry, presentation and information retrieval for clinical tasks, and behaviour of terminology in software. The semantic interoperability dimension addressed the commensurability of different classifications used by members of the CHAMP Community of Learners.

IX.A.1 HL7 Template For Chronic Kidney Disease Discharge Summary

The HL7 Template supported the evaluation and classification of chronic kidney disease through provision of data entry to automatically calculate the glomerular filtration rate, which was used to classify the stage of chronic kidney disease.

The HL7 Template used SNOMED CT to concurrently code the etiology of kidney disease. The etiology was coded based on the Primary Renal Disease codes from the Canadian Organ Replacement Register. These codes overlapped with the European Dialysis and Transplant Association (EDTA) codes, which are a subset of SNOMED CT. This helps with the adoption of a common nomenclature worldwide.

For the practical data entry component of clinical pragmatics, there was evidence that discharge summaries based on the HL7 Template were of higher quality than ones produced by the same individual using the current method, that is, the Dictation and Transcription system. They were at most neutral with respect to practical data entry. It takes more time to complete an electronic discharge summary using the HL7 Template than the current method. This is a barrier to introducing electronic discharge summaries into hospital workflow. A few residents found the HL7 Template method easy as or easier to use than the Dictation and Transcription method. Part of the difficulty in producing a discharge summary with either method resides with the organization of the patient chart into folders (e.g., Physician's Orders, History and Physical, Progress Records, Consultations, Operation Record, Nursing Record, Graphic Records, Lab Records, Medication Records). The discharge summary tells a story that unfolds over time, so the HL7 Template aimed to capture that chronicity by separating the story into three sections: Admission Summary, Course in Hospital and Discharge Summary. The chart is only organized along a time dimension within each folder, so the residents reported that use of the HL7 Template led to a lot of jumping around in the chart.

For the presentation component of clinical pragmatics, there was general agreement that the layout was appropriate and the information expressed as expected.

For the information retrieval component of clinical pragmatics, the electronic discharge summary was linked to supporting information in the form of SNOMED CT concept descriptions and drug details from the Nova Scotia Formulary. The SNOMED goal is to *"ensure healthcare knowledge is more usable and accessible worldwide, across clinical specialties and sites of care"* (133)). Through introducing residents to SNOMED CT, the HL7 Template helps facilitate the adoption of a common nomenclature worldwide. SNOMED CT has become universally available as the nomenclature for the electronic health record in the United States and Great Britain. Canada is playing a leadership role in the formation of SNOMED SDO (Standards Development Organization), and SNOMED CT will become universally available for the Canadian electronic health record at the completion of that process (163).

It does not appear to be pragmatic to concurrently code all the content in the discharge summary. The clinical narrative sections of a discharge summary help establish context and must be maintained. Encoding of this narrative to UMLS concepts was possible through MetaMap Transfer, an automated method. The output of the MetaMap Transfer program was processed through a set of PERL programs with the intention of filtering to SNOMED CT concepts. The missing concepts in SNOMED CT are the brand names for medications. One way to address this deficit is to train clinicians to use the generic name for a medication. Another way is to constrain the terminology to SNOMED CT and map each generic name for a medication to its brand names as stored in the online database of the Nova Scotia Drug Formulary.

For the semantic interoperability dimension, the HL7 Template served as a prompt for pertinent information which could be reused to support information needs of administrators, medical educators and patients. The information in the electronic discharge summary was useful in completing portions of a Canadian Organ Replacement Register Registration Form, a semantic index for a Chronic Kidney Disease Case that could be used in medical education, and a longitudinal patient record based on the HL7 Care Record Summary.

IX.A.2 Semantic Index For Chronic Kidney Disease Case

The Semantic Index was created as a boundary object, which is *"an intellectual tool that is flexible enough to deal with needs and constraints of several parties while retaining a common identity across sites"* (34). The goal was to compare datasets from two jurisdictions, Halifax, Nova Scotia, and Sherbrooke, Quebec, and use information gained from the process to improve the HL7 Template described in section V.A.

The Semantic Index is based on common patterns for diagnoses, lab results and medication events. It facilitates scoring the quality of a discharge summary and determining if two versions of a discharge summary authored by the same individual are commensurate. The discharge summaries are indexed using a vector representing 84 subjects, which includes the 16 Markers of Disease Progression from the Western Health Information Collaboratory (5).

For the clinical pragmatics dimension, the Semantic Index facilitates information retrieval of like cases from the two jurisdictions. The Semantic Index for a patient case is composed of a vector representing the 17 disease groups in the Charlson Index for Disease Groups and a vector representing the six Complications of Diabetes.

For the semantic interoperability dimension, the Semantic Index facilitated exploration of different clusters of patient cases that arose from a feature vector more commonly used by administrators (Charlson Index) and a feature vector more commonly used by medical educators and patients (Complications of Diabetes).

IX.A.3 Clinical Document Repository

The heterogeneous sources of hospital data were normalized using three different schemas based on the HL7 Clinical Document Architecture (CDA). These were the CDA Quick Start for the minimum data elements, the HL7 Template for the Chronic Kidney Disease Discharge Summary and the HL7 Template for the Care Record Summary.

For the clinical pragmatics dimension, the Semantic Index for a Chronic Kidney Disease case facilitated retrieval of an item in the Clinical Document Repository. The Semantic Index was stored as a topic map and linked to the item. This separation of the index from the clinical document facilitated an item's retrieval based on disease groups, complications or clinical statement patterns for lab results and medication events.

For the semantic interoperability dimension, the Clinical Document Repository was a common point of reference for members of the CHAMP Community of Learners. The longitudinal patient record generated from multiple hospital visits was rendered as a patient journey that could be viewed across a time continuum, from retrospective to concurrent to prospective views. The clinical statement patterns facilitate integration with the Department of Medicine's Triage system, a system already used by clinicians and administrators.

IX.B Evaluation Of Boundary Infostructure For Inflammatory Bowel Disease

The goal of this infostructure is to answer questions posed by a test instrument using the Socratic Completeness method. The created boundary objects in the Inflammatory Bowel Disease infostructure are:

1. Semantic Index for IBD Factors

2. Patient Information Repository

3. Inflammatory Bowel Disease Topic Map

The analysis of clinician-clinician and clinician-patient communication confirmed that SNOMED CT is a common language used among members of the CHAMP Community of Learners. The results of the automated mapping of the Inflammatory Bowel Disease Text Corpus (Appendix B) showed that 96.6% of text strings that were codable to UMLS were mapped to the SNOMED CT source vocabulary in UMLS. This is a critical finding, since there is resistance to using SNOMED CT at a time when the government mandates the use of ICD-10-CA for diagnostic coding. The scope of concept coding should be broader than diagnoses. Use of SNOMED CT could help ensure a data collection that would be made available for knowledge discovery and links from activities to results.

Another advantage of using SNOMED CT, an analytico-synthetic classification system, is that it supports inferencing. This inferencing was demonstrated for the task of answering questions. SNOMED CT is distributed with three flat files—contents, descriptions and relationships—that could be readily loaded into a topic map applications. These files enable Description Logics to be used as a consistent way of representing the associations between concepts and making inferences. The Socratic Completeness method is an implementation of access-limited logic. It uses propositions to prove whether or not the answer to a question can be reached in a network-structured knowledge base.

The Inflammatory Bowel Disease virtual clinic on the HealthInfoRx™ server was not linked to external resources. In order to answer the questions posed in the CCKNOW instrument, the content should be converted to a Patient Information Repository and augmented with terminological knowledge and eHealth resources, such as the XML-based Structured Product Labeling records for drug inserts on the DailyMed resource maintained by the National Library of Medicine using drug inserts approved by the Food and Drug Administration. Through this augmentation, the information on a drug's side effects could be integrated with other content.

XML is a Semantic Web tool and was exploited for the pragmatic construction of a Semantic Index for each webpage in the Patient Information Repository.

The Topic Map enabled semantic interoperability among items in the Patient Information Repository. The communities of practice which the boundary infostructure is intended to serve are thus able to reach a common ground. The Topic Map is a boundary object that provides a common point of reference.

IX.C Further Work

Some of the roadblocks that were encountered arose from difficulties in recruiting medical clerks and residents to participate in a research study. Medical educators need to ensure that today's physicians-in-training are equipped with the knowledge, skills and attitudes to participate in an environment where eHealth resources will play an increasingly important role.

More integration with existing hospital information systems would improve the usability of the HL7 Template for Chronic Kidney Disease Discharge Summary. A discussion with Pathology Informaticians has confirmed that it should be doable to pre-populate the discharge summmary template with lab results. The task for the clinician would then be to choose which lab results are pertinent for a clinical communication. The Gricean maxims still apply, which are quantity, quality, relevance and manner (24).

The vast store of clinical documentation in clinical letters, referral letters and discharge summaries could be text mined to provide information for the generation of patient journeys. Such a use would facilitate planning for chronic disease management and palliative care management.

This research was a proof of concept. It demonstrated that boundary infostructures for chronic disease provided a solution to the semantic interoperability problem. It demonstrated that we could improve pragmatic communication through templates that pull information at the time of recordkeeping that can be pushed to patients and disease registries to fulfill other functions. The clinical pragmatics applications included feedback on the pertinence of lab workup and prompting for information required to facilitate triage. These two applications have the potential to save human resources and material resources. Further research is needed for methods to reduce the burden of data entry; otherwise, it will not be practical to introduce template-based discharge summaries as a routine activity.

BIBLIOGRAPHY

(1) Coiera E. Guide to Health Informatics. 2nd ed. London, Great Britain: Arnold; 2003.

(2) Tang PC, Ash JS, Bates DW, Overhage JM, Sands DZ. Personal health records: definitions, benefits, and strategies for overcoming barriers to adoption. J.Am.Med.Inform.Assoc. 2006 Mar-Apr;13(2):121-126.

(3) Cariani P. Cybernetic systems and the semiotics of translation. In S.Petrilli (Ed.), *Translation.* Amsterdam: Rodopi; 2003:349 – 367.

(4) Grant AM, Moshyk AM, Kushniruk A, Moehr JR. Reflections on an arranged marriage between bioinformatics and health informatics. Methods Inf.Med. 2003;42(2):116-120.

(5) WHIC. *Western Health Information Collaborative (WHIC) chronic disease management (CDM) project phase 2.* 2006 January 4;Version 1.0; Available at: http://www.whic.org/public/profiles/cdm.html.

(6) Soroka SD, Hussey P, Douglas J. *Chronic kidney disease management project.* Halifax: Capital Health District Authority; 2002 July 4.

(7) Shepherd M, Zitner D, Watters C. Medical portals: web-based access to medical information. *IEEE Proceedings of the 33rd Hawaii International Conference on System Sciences* 2000:1-10.

(8) Zitner D. Teaching how IT can support patient care: Dalhousie University's Informatics program. *Future Practice* 2004;1(1):44-45.

(9) Hersh W. Who are the informaticians? What we know and should know. *J.Am.Med.Inform.Assoc.* 2006 Mar-Apr;13(2):166-170.

(10) Miller RH, Sim I. Physicians' Use Of Electronic Medical Records: Barriers And Solutions. *Health Aff* 2004;14(2):116-126.

(11) Kisely SR. Treatments for chronic fatigue syndrome and the Internet: a systematic survey of what your patients are reading. *Aust.N.Z.J.Psychiatry* 2002 Apr;36(2):240-245.

(12) Bowker GC, Star SL. *Sorting things out : classification and its consequences.* Cambridge, Mass.: MIT Press; 1999.

(13) Barnett GO. Report to the National Institutes of Health Division of Research Grants Computer Research Study Section on computer applications in medical communication and information retrieval systems as related to the improvement of patient care and the medical record--September 26, 1966. *J.Am.Med.Inform.Assoc.* 2006 Mar-Apr;13(2):127-35; discussion 136-7.

(14) Alschuler L. Doing Simple Things Simply and Complex Things Carefully: An Introduction to the CDA Value Proposition. *5th HL7 International Affiliate Meeting & 2nd International Conference on the CDA* Acapulco: HL7; 2004 October 18-22.

(15) Gal U, Yoo Y, Boland RJ. The Dynamics of Boundary Objects, Social Infrastructures and Social Identities. *Sprouts: working papers on information environments, systems, and organizations.* 2004;4(4):193-206; Available at: http://sprouts.case.edu/2004/040411.pdf.

(16) Murray, James Augustus Henry. *Oxford English Dictionary (OED) Online. New Edition* Oxford, England: Oxford University Press; 2006; Available at: http://www.oed.com.

(17) Noseworthy T, Watanabe M. Health policy directions for evidence-based decision making in Canada. *J.Eval.Clin.Pract.* 1999 May;5(2):227-242.

(18) Advisory Council on Health Infostructure. *Tactical Plan for a pan-Canadian Health Infostructure: 2001 Update.* Ottawa: Health Canada; 2001.

(19) Wittgenstein L. *Philosophical Investigations: The German text, with a revised English translation.* Third ed. Malden, MA: Blackwell Publishing; 2001.

(20) Wrightson A. Models and Messages: Insights from the HL7/OMG Services Specification Project. *XML 2005 conference and exhibition*; 2005 November 14-18; Available at: http://www.idealliance.org/proceedings/xml05/abstracts/paper40.HTML.

(21) Leavitt M. Electronic Medical Records: Key to Quality and Customer Service and A Solution to the E/M Service Documentation Challenge. *MGMA 72nd Annual Conference*; October 6, 1998.

(22) Berners-Lee T, Hendler J, Lassila O. The semantic Web: a new form of Web content that is meaningful to computers will unleash a revolution of new possibilities. *Sci Amer* 2001 May 2001;284(5):34.

(23) Wenger E. *Cultivating communities of practice: a guide to managing knowledge.* Boston: Harvard University Press; 2002.

(24) Grice HP. Logic and conversation. In: Cole P, Morgan JL, editors. *Syntax and Semantics.* 3rd ed. New York: Academic Press; 1974. p. 41-58.

(25) Sutton SA. Future Service Models and the Convergence of Functions: The Reference Librarian as Technician, Author and Consultant. In: Low K, editor. *The Roles of Reference Librarians* Binghamton, NY: Haworth Press; 1996. p. 125-144.

(26) Paterson GI, Soroka SD. Formative Evaluation of the Clinical Pragmatic Attributes of Components Chosen for a Boundary Infostructure. *Proceedings of the 11th international symposium on health information management research - iSHIMR2006* 2006 July 14-16.

(27) Rector AL. Clinical terminology: why is it so hard? *Methods Inf.Med.* 1999 Dec;38(4-5):239-252.

(28) Park J, Hunting S editors. *XML topic maps: creating and using topic maps for the Web.* 1st ed. Boston, MA: Addison-Wesley; 2002.

(29) Crawford JM, Kuipers BJ. ALGERNON: A tractable system for knowledge-representation. *SIGART Bulletin* 1991 June 1991;2(3).

(30) Dolin RH, Alschuler L, Boyer S, Beebe C, Behlen FM, Biron PV, et al. HL7 Clinical Document Architecture, Release 2. *J.Am.Med.Inform.Assoc.* 2006 Jan-Feb;13(1):30-39.

(31) Mensink N, Ginn JL, Zitner D. Using Web-mediated Facilitation for Prevention of Illness and Promotion of Health in Patients with Chronic Diseases. *Atlantic Network for Prevention Research*; White Point Beach, Nova Scotia: Dalhousie University; 2005; Available at: http://preventionresearch.dal.ca/pdf/ANPR_Program.pdf.

(32) Paterson GI, Ginn JL, Leddin DJ, MacIntosh DG, Stewart JE, Zitner D. Interprofessional Development of Learning Resources for IBD Patient Portal. *11th world congress on internet in medicine (MedNet2006)* 2006 October 13-20; Available at: http://www.mednetcongress.org/ocs/viewabstract.php?id=153

(33) Bishop AP, Neumann LJ, Star SL, Merkel C. Digital libraries: Situating use in changing information infrastructure. *JASIS* 2000 Mar 1, 2000;51(4):394.

(34) Star SL, Griesemer JR. Institutional Ecology, Translations and Boundary Objects: Amateurs and Professionals in Berkeley's Museum of Vertebrate Zoology 1907-39. *Social Studies of Science* 1989;19:387-420.

(35) Star SL, Bowker GC. Work and Infrastructure. *Communications of the ACM* 1995 September 1995;38(9):41.

(36) Carlile PR. A Pragmatic View of Knowledge and Boundaries: Boundary Objects in New Product Development. *Organization Science* 2002 Jul/Aug;13(4):442-455.

(37) World Health Organization. *eHealth.* 2005. Fifty-Eighth World Health Assembly. 2005 April 7; Available at: http://www.who.int/gb/ebwha/pdf_files/WHA58/A58_21-en.pdf

(38) Health Canada. *eHealth InfoSource cybersanté.* Available at: http://www.hc-sc.gc.ca/ohih-bsi/pubs/bulletin/infosource_e.html.

(39) Berg M. Medical work and the computer-based patient record: a sociological perspective. *Methods Inf Med* 1998;37:294-301.

(40) McDonald CJ. The barriers to electronic medical record systems and how to overcome them. *J.Am.Med.Inform.Assoc.* 1997 May-Jun;4(3):213-221.

(41) Lindberg DA. Commentary on G. Octo Barnett's Report to the Computer Research Study Section. *J.Am.Med.Inform.Assoc.* 2006 Mar-Apr;13(2):136-137.

(42) Health Canada. *Request for applications for primary research projects innovation in the health system: Ehealth - RFA 022.* 2005; Available at: http://www.hc-sc.gc.ca/sr-sr/finance/hprp-prpms/complet-term/rfa-da-022_e.html. Accessed August 7, 2006.

(43) Jones R, Rogers R, Roberts J, Callaghan L, Lindsey L, Campbell J, et al. What Is eHealth (5): A Research Agenda for eHealth Through Stakeholder Consultation and Policy Context Review. *J Med Internet Res* 2005;7(5):e54.

(44) Kazimirski M, Renaud C, Sawaya L, Zitner D, Korman R. Computer Literacy and Electronic Medical Records. The College of Family Physicians of Canada 2000; Available at: http://informatics.medicine.dal.ca/files/computer%20literacy.pdf

(45) Ford EW, Menachemi N, Phillips MT. Predicting the adoption of electronic health records by physicians: when will health care be paperless? *J.Am.Med.Inform.Assoc.* 2006 Jan-Feb;13(1):106-112.

(46) van Ginneken AM. The computerized patient record: balancing effort and benefit. *Int.J.Med.Inform.* 2002 Jun;65(2):97-119.

(47) Zitner D. Physicians will happily adopt information technology. *CMAJ 2006* May 23;174(11):1583-1584.

(48) Currell R, Urquhart C. Nursing record systems: effects on nursing practice and health care outcomes. *Cochrane Database of Systematic Reviews 2003, Issue 3* Art. No.: CD002099.

(49) Poissant L, Pereira J, Tamblyn R, Kawasumi Y. The impact of electronic health records on time efficiency of physicians and nurses: a systematic review. J.Am.Med.Inform.Assoc. 2005 Sep-Oct;12(5):505-516.

(50) Gillis G, editor. IHE Canada (Integrating the Healthcare Enterprise). *Partnership for health information standards fall 2005 symposium: conform to the norm*; Toronto, ON: Canadian Institute for Health Information; 2005 November 15-17.

(51) Handler T, Holtmeier R, Metzger J, Overhage M, Taylor S, Underwood C. *HIMSS Electronic Health Record Definitional Model Version 1.1.* 2003; Available at: http://www.himss.org/content/files/ehrattributes070703.pdf, June, 2006.

(52) Star SL, Ruhleder K. *Steps towards an ecology of infrastructure: complex problems in design and access for large-scale collaborative systems.* 1994 October 22 - 26.

(53) Walsh S. H. The clinician's perspective on electronic health records and how they can affect patient care. *BMJ* 2004 May 15;328(7449):1184-1187.

(54) Urquhart C, Currell R. Reviewing the evidence on nursing record systems. In Bath P, editor. *Proceedings of ninth international symposium on health information management research – iSHIMR2004* Sheffield: University of Sheffield; 2004 June 15-17.

(55) King JL, Star SL. Conceptual foundations for the development of organizational decision support systems. *IEEE proceedings of the twenty-third annual Hawaii international conference on system sciences*; 1990 January 2-5.

(56) *Discharge Summary Training Manual: Purposes and Specifics of Discharge Summaries.* Department of Medicine; Dalhousie University, Halifax, NS; 2003 Dec 02.

(57) Maicher L. Subject identification in topic maps in theory and practice. *Proceedings of Berliner XML Tage 2004*; 2004 October 11-13; Available at: http://www.informatik.uni-leipzig.de/~maicher/publications/[maic04cFINAL].pdf

(58) *SNOMED clinical terms technical reference guide.* Northfield, IL: College of American Pathologists; 2005.

(59) Ogden CK, Richards IA. *The meaning of meaning: a study of the influence of language upon thought and of the science of symbolism.* 5th ed. London: Kegan Paul, Trench, Trubner & Co.; 1938.

(60) Russler DC, Schadow G, Mead C, Snyder T, Quade LM, McDonald CJ. Influences of the unified service action model on the hl7 reference information model. *Proceedings of the American medical informatics association fall symposium.* 1999:930-934.

(61) Burgun A. Desiderata for domain reference ontologies in biomedicine. *J.Biomed.Inform.* 2006 Jun;39(3):307-313.

(62) Bodenreider O, Mitchell JA, McCray AT. Evaluation of the UMLS as a terminology and knowledge resource for biomedical informatics. *Proceedings of the American medical informatics association fall symposium.* 2002:61-65.

(63) Smith B, Ceusters W, Temmerman R. Wusteria. *Stud.Health Technol.Inform.* 2005;116:647-652.

(64) Cote RA, Rothwell DJ. The classification-nomenclature issues in medicine: a return to natural language. *Med.Inform.(Lond)* 1989 Jan-Mar;14(1):25-41.

(65) Rothwell DJ, Cote RA. Managing information with SNOMED: understanding the model. *Proceedings of the American medical informatics association fall symposium.* 1996:80-83.

(66) Rothwell DJ, Cote RA, Cordeau JP, Boisvert MA. Developing a standard data structure for medical language--the SNOMED proposal. *Proceedings of the annual symposium on computer applications in medical care.* 1993:695-699.

(67) Sager N, Lyman M, Nhan NT, Tick LJ. Medical language processing: applications to patient data representation and automatic encoding. *Methods Inf.Med.* 1995 Mar;34(1-2):140-146.

(68) Ingenerf J, Reiner J, Seik B. Standardized terminological services enabling semantic interoperability between distributed and heterogeneous systems. *Int.J.Med.Inform.* 2001 Dec;64(2-3):223-240.

(69) National Library of Medicine. *UMLS Knowledge Sources.* 2006; Available at: http://www.nlm.nih.gov/research/umls/umlsdoc.html. Accessed August 7.

(70) Athreya BH, Cheh ML, Kingsland LC,3rd. Computer-assisted diagnosis of pediatric rheumatic diseases. *Pediatrics* 1998 Oct;102(4):E48.

(71) Johnson PD, Tu SW, Musen MA, Purves I. A virtual medical record for guideline-based decision support. *Proceedings of the American medical informatics association fall symposium.* 2001:294-298.

(72) Strang N, Cucherat M, Boissel JP. Which coding system for therapeutic information in evidence-based medicine. *Comput.Methods Programs Biomed.* 2002 Apr;68(1):73-85.

(73) Campbell JR, Carpenter P, Sneiderman C, Cohn S, Chute CG, Warren J. Phase II evaluation of clinical coding schemes: completeness, taxonomy, mapping, definitions, and clarity. CPRI Work Group on Codes and Structures. *J.Am.Med.Inform.Assoc.* 1997 May-Jun;4(3):238-251.

(74) Cimino JJ. In defense of the Desiderata. *J.Biomed.Inform.* 2006 Jun;39(3):299-306.

(75) Cimino JJ. Desiderata for controlled medical vocabularies in the twenty-first century. *Methods Inf.Med.* 1998 Nov;37(4-5):394-403.

(76) Chute CG, Elkin PL, Sherertz DD, Tuttle MS. Desiderata for a clinical terminology server. *Proceedings of the American medical informatics association fall symposium.* 1999:42-46.

(77) Cimino JJ, Patel VL, Kushniruk AW. Studying the human-computer-terminology interface. *J.Am.Med.Inform.Assoc.* 2001 Mar-Apr;8(2):163-173.

(78) Rosenbloom ST, Miller RA, Johnson KB, Elkin PL, Brown SH. Interface terminologies: facilitating direct entry of clinical data into electronic health record systems. *J.Am.Med.Inform.Assoc.* 2006 May-Jun;13(3):277-288.

(79) Ruan W, Buerkle T, Dudeck JW. Mapping various information sources to the semantic network of the giessen data dictionary server. *Medinfo* 2004;2004:430-433.

(80) Bowker G, Star SL. Situations vs. standards in long-term, wide-scale decision-making: the case of the International Classification of Diseases. *IEEE proceedings of the twenty-fourth annual Hawaii international conference on system sciences*; 1991 January 8-11.

(81) Berg M, Goorman E. The contextual nature of medical information. *Int.J.Med.Inform.* 1999 Dec;56(1-3):51-60.

(82) Wagner EH, Bennett SM, Austin BT, Greene SM, Schaefer JK, Vonkorff M. Finding common ground: patient-centeredness and evidence-based chronic illness care. *J.Altern.Complement.Med.* 2005;11 Suppl 1:S7-15.

(83) Roshandel D, Rezailashkajani M, Ansari S, Zali MR. Internet use by a referral gastroenterology clinic population and their medical information preferences. *Int.J.Med.Inform.* 2005 Jul;74(6):447-459.

(84) Weingart SN, Rind D, Tofias Z, Sands DZ. Who uses the patient internet portal? The PatientSite experience. *J.Am.Med.Inform.Assoc.* 2006 Jan-Feb;13(1):91-95.

(85) Bellazzi R, Arcelloni M, Bensa G, Blankenfeld H, Brugues E, Carson E, et al. Design, methods, and evaluation directions of a multi-access service for the management of diabetes mellitus patients. *Diabetes Technol.Ther.* 2003;5(4):621-629.

(86) Rezailashkajani M, Roshandel D, Ansari S, Zali MR. Knowledge of disease and health information needs of the patients with inflammatory bowel disease in a developing country. *Int.J.Colorectal Dis.* 2006 Jul;21(5):433-440.

(87) Cork RD, Detmer WM, Friedman CP. Development and initial validation of an instrument to measure physicians' use of, knowledge about, and attitudes toward computers. *J.Am.Med.Inform.Assoc.* 1998 Mar-Apr;5(2):164-176.

(88) Bandholtz T. *A taxi in knowledge land: a use case that combines topic maps and web services in a public portal* 2003; Available at: http://www.idealliance.org/papers/xmle02/dx_xmle02/papers/03-05-03/03-05-03.html

(89) Gardner M. Why clinical information standards matter. *BMJ* 2003 May 24;326(7399):1101-1102.

(90) Kay S, Marley T, Toft C, Rector A, Purves I, Booth N, et al. CEN TC251 PT1-026 Extended Architecture and Domain Model for the Electronic Health Care Record. Comite Europeen de Normalisation (CEN) Technical Committee 251 (TC251) Project Team 26 1998 May 12, 1998.

(91) Rossi-Mori A, Consorti F. Structures of clinical information in patient records. *Proceedings of the American medical informatics association fall symposium.* 1999:132-136.

(92) Hammond EW. Method for the development of messages: A process for developing comprehensive, interoperable and certifiable data exchange among independent systems. *ISO Bulletin* 2002 August.

(93) Beale T. Unified EHR standards--is convergence possible? *Stud.Health Technol.Inform.* 2002;87:78-97.

(94) Schloeffel P. Current EHR Developments: an Australian and International Perspective - Part 2. *Health Care and Informatics Review Online* 2004 September 1.

(95) Rossi-Mori A, Rector A. Short Strategic Study on International Cooperation on Issues of Terminology. *CEN/TC251 WGII 2000*; Available at: http://www.centc251.org/WGII/N-00/WGII-N00-15.pdf

(96) Schloeffel P, Richards J. Standards Requirements for the Electronic Health Record & Discharge/Referral Plans. *ISO/TC 215 Ad Hoc Group Report*; 2002 July 26; Available at: http://www.gpcg.org/publications/docs/ISO_EHR_FinalReport.pdf

(97) Rossi-Mori A. *Clinical Templates, Registries and Terminologies.* Available at: http://www.hl7.org/Library/Committees/template/HL7St.Loius-templ-16.ppt. Accessed 11/19, 2004.

(98) Beale T. Archetypes and the EHR. *Stud.Health Technol.Inform.* 2003;96:238-244.

(99) Mattison JE, Dolin RH, Laberge D. Managing the Tensions Between National Standardization vs. Regional Localization of Clinical Content and Templates. *Medinfo* 2004;2004:1081-1085.

(100) Grogan EL, Speroff T, Deppen SA, Roumie CL, Elasy TA, Dittus RS, et al. Improving documentation of patient acuity level using a progress note template. *J.Am.Coll.Surg.* 2004 Oct;199(3):468-475.

(101) Tierney WM, Beck EJ, Gardner RM, Musick B, Shields M, Shiyonga NM, et al. Viewpoint: a pragmatic approach to constructing a minimum data set for care of patients with HIV in developing countries. *J.Am.Med.Inform.Assoc.* 2006 May-Jun;13(3):253-260.

(102) Dolin RH, Mattison JE, Cohn S, Campbell KE, Wiesenthal AM, Hochhalter B, et al. Kaiser Permanente's Convergent Medical Terminology. *Medinfo* 2004;2004:346-350.

(103) Cox JL, Zitner D, Courtney KD, et al. Undocumented patient information: An impediment to quality of care. *AM J Med* 2003;114(3):211-216.

(104) Velde, Rudi van de, Degoulet P. *Clinical information systems : a component-based approach* New York: Springer; 2003.

(105) Portoni L, Combi C, Pinciroli F. User-oriented views in health care information systems. *IEEE Transactions on Biomedical Engineering* 2002 Dec;49(12):1387-1398.

(106) Osterlund CS. Combining Genres: How Practice Matters. *IEEE Proceedings of the 39th annual Hawaii international conference on the system sciences* 2006 January 2006.

(107) McKenzie L. *Interoperable Electronic Health Record(iEHR) approach to clinical documents.* 2006; Available at: http://www.infoway-inforoute.ca/Patient Care presentation.pdf.

(108) Wenger E. Communities of practice: The social fabric of a learning organization. *Healthc.Forum J.* 1996 Jul-Aug;39(4):20-26.

(109) Wenger E. Communities of Practice and Social Learning Systems. *Organization* 2000;7(2):225-246.

(110) Pawlowski SD, Robey D, Raven A. Supporting Shared Information Systems: Boundary Objects, Communities, and Brokering. *Proceedings of the 21st international conference on information systems* 2000 December 10-13:329-338.

(111) Murphy LD. Digital Documents in Organizational Communities of Practice: A First Look. *IEEE proceedings of the 34th annual Hawaii international conference on system sciences* 2001 January 03 - 06, 2001:4005.

(112) Puustinen R. Bakhtin's philosophy and medical practice--toward a semiotic theory of doctor-patient interaction. *Med.Health Care Philos.* 1999;2(3):275-281.

(113) Durusau P, Newcomb S. *Topic Maps—Reference Model, 13250-5 Version 6.0.* 2005 July 13.

(114) Dudeck J, Schweiger R. SNOMED CT Representation in an Intelligent Search Engine Based on XML and Topic Maps (LUMRIX). *5th HL7 international affiliate meeting & 2nd international conference on the CDA* 2004 October 18-22; Available at: Available at: http://www.hl7.de/iamcda2004/finalmat/day2/LuMriX%20SNOMED%20CT%20Acapulco.pdf.

(115) Paterson GI, Abidi SS, Soroka SD. HealthInfoCDA: Case Composition Using Electronic Health Record Data Sources. *Stud.Health Technol.Inform.* 2005;116:137-142.

(116) Coping with the Introduction of ICD-10-CA and CCI: Impact of New Classifications Systems on the Assignment of Case Mix Groups/Day Procedure Groups Using Fiscal 2001-2002 Data. 2003.

(117) Needham DM, Scales DC, Laupacis A, Pronovost PJ. A systematic review of the Charlson comorbidity index using Canadian administrative databases: a perspective on risk adjustment in critical care research. *J.Crit.Care* 2005 Mar;20(1):12-19.

(118) Sundararajan V, Henderson T, Perry C, Muggivan A, Quan H, Ghali WA. New ICD-10 version of the Charlson comorbidity index predicted in-hospital mortality. *J.Clin.Epidemiol.* 2004 Dec;57(12):1288-1294.

(119) Alvarez RC. The promise of e-Health – a Canadian perspective. *The Journal of Applied Health Technology* 2002;1(4).

(120) Frank JR, Jabbour T, Tugwell P, et al. Skills for the new millennium: report of the Societal Needs Working Group, CanMeds 2000 Project. *Annals Royal College of Physicians and Surgeons of Canada* 1996;29;206-216.

(121) Paterson GI, Kaufman DM. Medical Informatics and Problem-Based Learning in Conjunction. *MedInfo* 1995;2:1149-1153.

(122) Gillis G, Richards J. Maintenance, conformance & compliance strategy project. *Partnership for health information standards fall symposium*; Toronto: CIHI; 2004; Available at: http://secure.cihi.ca/cihiweb/en/downloads/event_partner_oct04_main_con_com_e.pdf

(123) Kamel Boulos MN, Roudsari AV, Carso NER. HealthCyberMap: a semantic visual browser of medical Internet resources based on clinical codes and the human body metaphor. *Health.Info Libr.J.* 2002 Dec;19(4):189-200.

(124) Advisory Council on Health Infostructure. *Tactical Plan for a pan-Canadian Health Infostructure: 2001 Update.* 2001; Available at: http:///www.hc-sc.gc.ca/ohih-bsi/pubs2001_plan/plan_2001_3.pdf. Accessed Oct. 19, 2004.

(125) Fyke KJ. *Caring for Medicare. sustaining a quality system.* 2001; Available at: http://www.health.gov.sk.ca/mc_dp_commission_on_medicare-bw.pdf

(126) Itälä T, Virtanen A, Mikola T, et al.. Seamless Service Chains and Information Processes. *IEEE proceedings of the 38th annual Hawaii international conference on system sciences (HICSS'05)*; January 3-6, 2005; Washington, DC: IEEE Computer Society; 2005.

(127) Itälä T. CDA in Finland. *5th HL7 International Affiliate Meeting & 2nd International Conference on the CDA;* October 18-22; Germany: HL7; 2004.

(128) Alvarez R. Canada to work with other nations on HIT issues. *Canadian Healthcare Technology E-Newsletter* 2006 May 25, 2006;3(10).

(129) Catz M, Bayne J. Canada Health Infoway - a pan-Canadian approach. *Proceedings of the American medical informatics association fall symposium* 2003:807.

(130) Advisory Council on Health Infostructure. *Canada Health Infoway: Paths to Better Health: Final Report.* 1999; Available at: http://www.hc-sc.gc.ca/ohih-bsi/pubs/1999_pathsvoies/fin-rpt_e.pdf. Accessed December 2, 2004.

(131) Canada Health Infoway, *2003-2004 Annual Report and Corporate Plan Summary 2004-2005.* Available at: http://www.infoway-inforoute.ca.

(132) Gordon C, Gray JA, Toth B, Veloso M. Systems of evidence-based healthcare and personalised health information: some international and national trends. *Stud.Health Technol.Inform.* 2000;77:23-28.

(133) Côté RA, Bisson G. SNOMED and tools: current states and issues. *Partnership for health information standards;* Toronto, Canada: Canadian Institute for Health Information; 2004; Available at: http://secure.cihi.ca/cihiweb/en/downloads/event_partner_oct04_snomedtools_e.pdf.

(134) Spackman KA. Normal forms for description logic expressions of clinical concepts in SNOMED RT. *Proceedings of the American medical informatics association symposium.* 2001:627-631.

(135) Penz JF, Brown SH, Carter JS, Elkin PL, Nguyen VN, Sims SA, et al. Evaluation of SNOMED-CT Coverage of Veterans Health Administration Terms. *Medinfo* 2004;2004:540-544.

(136) de Lusignan S, Minmagh C, Kennedy J, Zeimet M, Bommezijn H, Bryant J. A survey to identify the clinical coding and classification systems currently in use across Europe. *Medinfo* 2001;10(Pt 1):86-89.

(137) Levy B. Evolving to Clinical Terminology. *J Healthc Inf Manag.* 2004;18(3):37-43.

(138) Bates DW, Ebell M, Gotlieb E, Zapp J, Mullins HC. A proposal for electronic medical records in U.S. primary care. *J.Am.Med.Inform.Assoc.* 2003 Jan-Feb;10(1):1-10.

(139) Liaw ST, Sulaiman N, Pearce C, Sims J, Hill K, Grain H, et al. Falls prevention within the Australian general practice data model: methodology, information model, and terminology issues. *J.Am.Med.Inform.Assoc.* 2003 Sep-Oct;10(5):425-432.

(140) Achieving Electronic Connectivity in Healthcare. A Preliminary Roadmap from the Nation's Public and Private-Sector Healthcare Leaders. 2004; Available at: http://www.markle.org/downloadable_assets/cfh_roadmap_final_071404.pdf. Accessed 11/19, 2004.

(141) BiRD: A Strategy to Autonomously Supplement Clinical Practice Guidelines with Related Clinical Studies. *IEEE proceedings of the 38th annual Hawaii international conference on system sciences (HICSS'05)* 2005 January 3-6.

(142) Peleg M, Boxwala AA, Tu S, Zeng Q, Ogunyemi O, Wang D, et al. The InterMed approach to sharable computer-interpretable guidelines: a review. *J.Am.Med.Inform.Assoc.* 2004 Jan-Feb;11(1):1-10.

(143) Kaufman DM. Integrating medical informatics into an undergraduate medical curriculum. *Medinfo* 1995;8 Pt 2:1139-1143.

(144) Allen MJ, Kaufman DM, Barrett A, Paterson G, Sargeant J, McLeod R. Self-reported effects of computer workshops on physicians' computer use. *J.Contin.Educ.Health Prof.* 2000 Winter;20(1):20-26.

(145) Cruess RL, Cruess SR. Teaching professionalism: general principles. *Med.Teach.* 2006 May;28(3):205-208.

(146) Mann KV. Thinking about learning: implications for principle-based professional education. J.Contin.Educ.Health Prof. 2002 Spring;22(2):69-76.

(147) Frank JR. The CanMEDS 2005 physician competency framework. better standards. better physicians. better care. 2005; Available at: http://meds.queensu.ca/medicine/obgyn/pdf/CanMEDS2005.booklet.pdf.

(148) Spackman KA, Campbell KE, Cote RA. SNOMED RT: a reference terminology for health care. *Proceedings of the American medical informatics association fall symposium* 1997:640-644.

(149) Dolin RH, Spackman KA, Markwell D. Selective retrieval of pre- and post-coordinated SNOMED concepts. *Proceedings of the American medical informatics association fall symposium* 2002:210-214.

(150) Green JM, Wilcke JR, Abbott J, Rees LP. Development and evaluation of methods for structured recording of heart murmur findings using SNOMED-CT post-coordination. *J.Am.Med.Inform.Assoc.* 2006 May-Jun;13(3):321-333.

(151) Spyropoulos B, Papagounos G. A theoretical approach to artificial intelligence systems in medicine. *Artif.Intell.Med.* 1995 Oct;7(5):455-465.

(152) Zitner D, Paterson GI, Fay D. Methods in Health Decision Support Systems: Methods for Identifying Pertinent and Superfluous Activity. In: Tan J, Sheps S, editors. *Health Decision Support Systems.* 1st Edition ed. New York: Aspen Publishers; 1998. p. 177-197.

(153) Hardy J, Weston R. Is Dementia with Lewy Bodies and Parkinson's Disease One Disorder or Two? Moving Along 2003;5(3):4-4.

(154) Cumulative Official Updates to ICD10. 2006; Available at: http://www.who.int/classifications/committees/ICDCombinedUpdates.pdf, July 6, 2006.

(155) Standards for Coded Clinical Data Essential to the Electronic Health Record. NLM Guide to the APHA 2005 Meeting; December 14-15, 2005; Bethesda, MA: National Library of Medicine; 2005.

(156) Mullins HC, Scanland PM, Collins D, Treece L, Petruzzi P,Jr, Goodson A, et al. The efficacy of SNOMED, Read Codes, and UMLS in coding ambulatory family practice clinical records. *Proceedings of the American medical informatics association fall symposium.* 1996:135-139.

(157) Canadian Coding Standards for ICD-10-CA and CCI, 2006. 2006 February 28, 2006.

(158) Grant A, Moshyk A, Boisvert M, Grondin R, Desautels M, De Lorenzi F, et al. Evaluation of a Snomed Coding Tool Integrated with a Hospital Data Warehouse Information Management System. *June 2003 workshop CIHR PhD/Postdoc strategic training program in health informatics;* Victoria, BC: 2003 June 19-21.

(159) Lussier YA, Rothwell DJ, Cote RA. The SNOMED model: a knowledge source for the controlled terminology of the computerized patient record. *Method Inf Med* 1998;37(2):161-164.

(160) Cote RA. Standardized coding of the medical problem list. *J.Am.Med.Inform.Assoc.* 1995 Jan-Feb;2(1):68.

(161) Pratt AW. Medicine, Computers, and Linguistics. *Advanc. Biomed. Engng* 1973;3:97-140.

(162) Health Information Technology Leaders from Canada, U.S., England, and Australia agree to collaborate on common issues and opportunities. 2006; Available at: http://www.infoway-inforoute.ca/en/News-Events/InTheNews_long.aspx?UID=213. Accessed August 14, 2006.

(163) Boudreau A. Why SNOMED CT? Why Clinical Terminology Standards? *Canada Health Infoway* November 2005.

(164) McClellan WM, Knight DF, Karp H, Brown WW. Early detection and treatment of renal disease in hospitalized diabetic and hypertensive patients: important differences between practice and published guidelines. *Am.J.Kidney Dis.* 1997 Apr;29(3):368-375.

(165) Tannen RL editor. *A Quarter century of nephrology : commemorating the American Society of Nephrology's 25th anniversary.* Baltimore, MD: Williams & Wilkins; 1992..

(166) Gruen RL, Knox S, Britt H, Bailie RS. The Surgical Nosology in Primary-care Settings (SNIPS): a simple bridging classification for the interface between primary and specialist care. *BMC Health Services Research* 2004 13 May 2004;4(8).

(167) Ranganathan SR. *Prolegomena to Library Classification.* Faridabad: Thomson Press (India) Ltd.; 1967.

(168) Shepherd MA, Watters CR. Implementation of facet-based retrieval using a relational database management system. In Rajagopalan TS, editor. *Proceedings of the international conference on Ranganathan's philosophy: assessment, impact and relevance* New Delhi; 1985 November 11-14.

(169) Schweiger R, Hoelzer S, Rudolf D, Rieger J, Dudeck J. Linking clinical data using XML topic maps. *Artif.Intell.Med.* 2003 Jun;28(1):105-115.

(170) Pisanelli DM, Gangemi A, Steve G. An ontological analysis of the UMLS Metathesaurus. *Proceedings of the American medical informatics association fall symposium.* 1998:810-814.

(171) Henry SB, Mead CN. Nursing classification systems: necessary but not sufficient for representing "what nurses do" for inclusion in computer-based patient record systems. *J.Am.Med.Inform.Assoc.* 1997 May-Jun;4(3):222-232.

(172) Elkin PL, Brown SH. Automated enhancement of description logic-defined terminologies to facilitate mapping to ICD9-CM. *J.Biomed.Inform.* 2002 Oct-Dec;35(5-6):281-288.

(173) Jacquelinet C, Burgun A, Delamarre D, Strang N, Djabbour S, Boutin B, et al. Developing the ontological foundations of a terminological system for end-stage diseases, organ failure, dialysis and transplantation. *Int.J.Med.Inform.* 2003 Jul;70(2-3):317-328.

(174) Jacquelinet C. Modelling Syllepse in Medical Knowledge Bases with Application in the Area of Organ Failure and transplantation. *Ontolex 2000 (workshop on ontologies and lexical knowledge base)*; Sozopol, Bulgaria; September 8-10, 2000.

(175) Golden JL, Rosenberg CE. *Framing Disease: Studies in Cultural History.* New Brunswick, NJ: Rutgers University Press; 1992.

(176) Bowker GC, Star SL. *Sorting Things Out: Classification and Its Consequences.* 1st ed. Cambridge, Mass: MIT Press; 1999.

(177) Ruelland A, Jaulent MC, Ota M, Frandji B, Degoulet P. Pragmatic objects modeling environment for Electronic Health Records Systems. *Stud.Health Technol.Inform.* 2003;95:328-333.

(178) Garshol LM. Metadata? Thesauri? Taxonomies? Topic Maps! Making Sense of it all. *J.Inf.Sci.* 2004;30(4):378.

(179) Ahmed K. Topic Map Design Patterns For Information Architecture. XML Europe, Londra 2003:5-8.

(180) Kneebone R. Evaluating clinical simulations for learning procedural skills: a theory-based approach. *Acad.Med.* 2005 Jun;80(6):549-553.

(181) Kenny NP, Mann KV, MacLeod H. Role modeling in physicians' professional formation: reconsidering an essential but untapped educational strategy. *Acad.Med.* 2003 Dec;78(12):1203-1210.

(182) Mann R, Williams J. RCP record keeping standards – inpatients Version 5.0. *Health informatics unit, The Royal College of Physicians of London*; 2004 July 22; Available at: http://hiu.rcplondon.ac.uk/clinicalstandards/recordsstandards/rec_standards.asp

(183) Mann R, Williams J. Standards in medical record keeping. *Clin.Med.* 2003 Jul-Aug;3(4):329-332.

(184) Carroll L. *Alice in Wonderland.* London: Barta Press; 1865.

(185) Portugali, J. Shannonian, semantic and pragmatic geoinformation. *Proceedings of the 12th international conference on geoinformatics*; Sweden: University of Gävle; 2004 June.

(186) Sigel A. *kPeer as a Context-Aware Topic Map P2P Application for the Distributed Integration of Knowledge.* 2004; Available at: http://kpeer.wim.uni-koeln.de/~sigel/veroeff/MRC2004/Sigel_MRC2004_updated.pdf, November 26, 2005.

(187) ISO. *Information Technology — Topic Maps — Part 2: Data Model.* 2005-10-28;ISO/IEC FDIS 13250-2.

(188) Kipp NA. *A mathematical formalism for the Topic Maps reference model.* URL: http://www.isotopicmaps.org/tmrm-/0441.htm 2003.

(189) Gómez-Gauchía H, Díaz-Agudo B, González-Calero P. Two-layered approach to knowledge representation using conceptual maps and description logic. *1st International Conference on Concept Mapping,* Pamplona, Spain 2004.

(190) Clase CM, Garg AX, Kiberd BA. Classifying kidney problems: can we avoid framing risks as diseases? *BMJ* 2004 Oct 16;329(7471):912-915.

(191) Kuhn TS. *The Road Since Structure: philosophical essay, 1970-1993, with an autobiographical interview.* Chicago, Il.: University of Chicago Press; 2000.

(192) Bowker GC, Star SL. How things (actor-net) work: Classification, magic and the ubiquity of standards. *Philosophia* 1997;25(3-4):195-220.

(193) Pearce M. *National diabetes surveillance system reference document (V2.1).* Public Health Agency of Canada (PHAC) 2005 March 31.

(194) do Amaral MB, Roberts A, Rector AL. NLP techniques associated with the OpenGALEN ontology for semi-automatic textual extraction of medical knowledge: abstracting and mapping equivalent linguistic and logical constructs. *Proceedings of the American medical informatics association fall symposium* 2000:76-80.

(195) Rector AL. The interface between information, terminology, and inference models. *Medinfo* 2001;10(Pt 1):246-250.

(196) Abidi SS, Manickam S. Leveraging XML-based electronic medical records to extract experiential clinical knowledge. An automated approach to generate cases for medical case-based reasoning systems. *Int. J. Med. Inform.* 2002;68(1-3):187-203.

(197) Eshach H, Bitterman H. From case-based reasoning to problem-based learning. *Acad Med* 2003;78(5):491-496.

(198) Ceusters W, Smith B. Strategies for referent tracking in electronic health records. *Journal of biomedical informatics* 2006;39(3):362-378.

(199) C. Stigant, L. Stevens, A. Levin. "Nephrology: 4. Strategies for the Care of Adults with Chronic Kidney Disease." *Can. Med. Assoc. J.* 2003; 168:1553-1560. Available at http://www.cmaj.ca/cgi/reprint/168/12/1553.

(200) Alschuler Associates Inc. CDA support: Quick Start Guides. [updated January 2006]. Available from: http://www.alschulerassociates.com/cda/?topic=quick-start-guides.

(201) Aronson AR. Effective mapping of biomedical text to the UMLS Metathesaurus: the MetaMap program. *Proceedings of the American medical informatics association fall symposium.* 2001:17-21.

(202) Pereira S, Massari P, Joubert M, Fieschi M, Darmoni S. Utilisation de super-concepts pour la recherche d'information dans les dossiers médicaux. *JFIM 2007.* Available at http://cybertim.timone.univ-mrs.fr/recherche/doc-recherche/informatique/JFIM2007/

(203) Van Zanten S, Zitner D, Mann K. *Randomized clinical trial to improve the quality of discharge summaries of internal medicine residents using a discharge summary course.* Halifax, NS: Dalhousie University Division of Medical Education Research and Development Fund; 2001 November.

(204) Paterson GI, Fabry P, Grant AM, Thieu TT, Soroka SD, Diab H, Moshyk A. Semantic indexing of patient cases in a boundary infostructure for Ehealth. In Kushniruk A, editor. *Proceedings of information technology and communications in health (ITCH)* Victoria, BC; 2007 February 15-18.

(205) Markwell D. M3-Clinical Statements. *HL7 Working Group Meeting.* Phoenix, AZ; 2006 January 9.

Appendix A. Items In The Chronic Kidney Disease Text Corpus

The constrained terminology for the Boundary Infostructure for Chronic Kidney Disease was derived from a semantic analysis of the following items.

Printed pages in the patient chart (N=20) authored by Clinicians and Administrators:

Inpatient Admission Form

Clinic Letter

Drug Interaction Warnings

Laboratory Results

Surgical Pathology Report

Patient Diagnostic Imaging

Consent Form Radiology

Dictated and Transcribed and Electronic Discharge Summaries (N=13) authored by Clinicians

Canadian Institute for Health Information Discharge Abstract (N=2) authored by Administrators

Case, Skin, Glands and Blood Unit in Dalhousie University Case-Oriented Problem-Stimulated Undergraduate Medical Education Curriculum (N=1) authored by Medical Educator

Department of Medicine Triage and Wait Times (N=1) authored by Administrators

CIRESSS Dataset of Diagnosis, Procedure, Department, Service and Specialty (N=51485) authored by Health Informaticians

CIRESSS Dataset of Lab Test, Lab Result, Indicator, Date and Time (N=16487) authored by Health Informaticians

Appendix B. Items In The Inflammatory Bowel Disease Text Corpus

The constrained terminology for the Boundary Infostructure for Inflammatory Bowel Disease was derived from a semantic analysis of the following items.

Frequently Asked Questions (N=93) authored by Patients

Answers to Frequently Asked Questions (N=93) authored by Clinicians

Glossary (N=398) authored by Health Informaticians

Crohn's and Colitis Knowledge Test (N=24) authored by Clinician

Inflammatory Bowel Disease Questionnaire (N=1) authored by Clinician

Pamphlets (N=5) authored by Medical Educators

Cochrane Plain Language Summaries (N=10) authored by Patients

Discussion Group Threads (N=32) authored by Patients

Learning Modules (N=13) authored by Medical Educators

Continuing Education Module (N=1) authored by Medical Educator

Appendix C: Instruments Used In Transcription Versus Templates For Discharge Summary Study

The study was described in Chapter IV. Instruments were Figure C.1 Recruitment Questionnaire and Figures C.2, C.3 and C.4 Pages of Feedback Questionnaire. The Quick Start Guide provided instructions for direct data entry of discharge summary via a template.

Capital Health

Transcription versus Electronic Health Record Templates for Chronic Kidney Disease Discharge Summary

Recruitment Questionnaire

User number:

Please tick **only one** answer per question. Thank you.

Demographics:

What is your level of medical training? □ Clerk □ Resident □ Nurse Practitioner □ Nephrologist □ Other Physician

Is English the language that you first learned at home in childhood? □ Yes □ No

Computer Experience:

	Never	Once or Twice	Monthly	Weekly	Daily
I have used a word processor (e.g. MS Word) to compose a text document					
I have used a database program (e.g. Access)					
I have used an internet search engine (e.g. Google) to find clinical information					
I have searched the Medline database using the PubMed search engine					
I have used the Nova Scotia Formulary on the Department of Health website to search for drug information					

Medical Education:

I have received formal training regarding what content should be included in a discharge summary □ Yes □ No

I have previously used the Capital Health Enterprise Express Voice Dictation and Transcription System to dictate a Discharge Summary □ Yes □ No

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Figure C.1 Recruitment Questionnaire

Capital Health

Transcription versus Electronic Health Record Templates for Chronic Kidney Disease Discharge Summary Study

Feedback Questionnaire

User number:

Thank you for taking part in this study. We appreciate your taking the time to do this.

1. Please respond to the following statements regarding the Electronic Discharge Summary:

Statement	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
I was able to enter all the important data elements					
I found the diagnosis terms I needed in the Lookup List					
I found the laboratory terms I needed in the Lookup List					
I found the medications I needed via link to the Nova Scotia Drug Formulary					
I found that structuring content into Admission, Course in Hospital, and Discharge sections was relevant to me					
I am comfortable using a computer for data entry of discharge summaries					
I found the Electronic Discharge Summary easy to use					

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Figure C.2 Page 1 Of Feedback Questionnaire

2. Please respond to the following statements regarding the Transcription System:

Statement	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
I was able to enter all the important data elements					
I dictated in a way that makes it easy for transcriptionists to transcribe the dictation					
I was sufficiently informative for the purpose of a discharge summary					
I am comfortable using dictation for data entry of discharge summaries					
I found the **Transcription System** easy to use					

3. Rate the style of your discharge summary produced after you completed the **Electronic Discharge Summary**:

	Agree	Neutral	Disagree
Colour choices were appropriate			
Layout was logical			
Text was large enough			
Information was expressed as expected			
Amount of content was appropriate			

4. The discharge summary was automatically coded to the SNOMED CT nomenclature at the time of data entry. Did you access the terminological knowledge available via links from the codes in your electronic discharge summary?

   ○ Yes ○ No

   If yes, did it enhance your understanding of the terminology used:

   ○ Yes ○ No

Figure C.3 Page 2 Of Feedback Questionnaire

5. The hospital produces a discharge abstract for the Canadian Institute for Health Information (CIHI) that is coded to the International Classification of Disease Version 10 (ICD-10-CA). Did you access the CIHI discharge abstract for this patient encounter that was provided as feedback?

☐ Yes ☐ No

If yes, was this feedback helpful in understanding how the information you enter is coded for reimbursement and epidemiology purposes:

☐ Yes ☐ No

6. Did you seek information in the Chronic Kidney Disease HL7 Templates User Guide (placed in binder with patient chart)?

☐ Yes ☐ No

If yes, was it helpful:

☐ Yes ☐ No

7. Did you seek information in the Discharge Summary Training Manual via ? in the online form?

☐ Yes ☐ No

If yes, was it helpful:

☐ Yes ☐ No

8. Please give us any suggestions you have for improvement below; use the back of the page if you require additional space.

Figure C.4 Page 3 Of Feedback Questionnaire

Transcription Versus Electronic Health Record Templates For Chronic Kidney Disease Discharge Summary

Investigators: Grace Paterson, Medical Informatics and Dr. Steven Soroka, Nephrology

Quick START GUIDE

GENERAL INFORMATION:
Note: **Requires Internet Explorer Version 6 or later**
The electronic discharge summary contains links highlighted in green (ICD10 Online; Lookup NS Formulary), buttons (Add Another; GFR Calculation; CKD Diagnosis; Co-morbidity Lookup; Lookup Lab Tests; Save CDA XML) and drop-down menus. Click on these to activate them. For additional details or related figures, see the User Manual in the binder.

TO LOG IN:
Go to http://www.healthinforx.ca/. Click on CKD Clinic. Enter your number as Username and Password. The form is a template to guide your dictation or data entry. You may choose to either dictate or data enter.

Section	Data Entry into Computer	Dictation into Device
Site	Click on drop-down menu and select appropriate location.	Say "Site is" (and give site)
Report to	Type in appropriate data in each field. Use "add another" if more than one referral and repeat as needed.	Say " Report copy to" (and give person's name, suffix, speciality and address; repeat as needed for others)
Patient Information:	Type in appropriate data in each field; use drop-down menus for sex and dates.	Say "Patient information". Say the field name, (e.g. hospital unit number) and give the value.
Admission Information (including Health Status)	Use buttons, links and typing in data to fill in each field.	Say "Part I Admission Information". A) Use the GFR calculator to obtain the stage and then say "Stage" and give value. Click on CKD Diagnosis, say "Admission Diagnosis", and give your selection from the list. Enter reason if diagnosis is not for renal failure. B) Click on the Co-morbidity Lookup and say "Co-morbidity"; give diagnosis code, description, status choice (unknown, yes or no) and date diagnosed with that disease. If not found in Lookup, click on ICD10 Online for additional diagnoses codes. C) Say "Health Status" and give status.
History of Present Illness (including Relevant Past Medical and Surgical History, Allergies and Adverse Reactions & Social)	Type in appropriate data in each field; use "add another" if necessary in Allergies section.	Say "History of Present Illness" and give narrative description. Say "Relevant Past Medical and Surgical History" and give narrative description. Say "Allergies and Adverse Reactions" and give narrative description. Say "Social" and give narrative description.
Family History	Use drop-down menu and type in data for each field; use "add another" if necessary.	Say "Family History" and give details.
Immunizations	Use drop-down menu and type in data for each field; use "add another" if necessary.	Say "Immunizations" and give details
Physical Examination	Use drop-down menu and type in data for each field; use "add another" if necessary	Say "Physical Examination" and give details including vital signs
Laboratory Results:	Use drop-down menu and type in data for each field; use "add another" if necessary.	Say "Relevant Lab Data on Admission", click on Lookup Lab Tests, say your selections and give the lab results.

Section	Data Entry into Computer	Dictation into Device
Physician on Admission	For this study, these fields are filled in and locked.	No action is necessary.
Course in Hospital (including Procedures Performed and Relevant Lab Data)	Use drop-down menu and type in data for each field; use "add another" if necessary.	Say "Part II Course in Hospital" a) Give narrative description and give details about procedures done. b) Say "Relevant Lab Data in Hospital", click on Lookup Lab Tests, say your selections and give the lab results.
Discharge Diagnosis	Use drop-down menu and type in data for each field; use "add another" if necessary. Use link for further information.	Say "Part III Discharge Information" A) Use the GFR calculator to obtain the stage and then say "Stage" and give value. Click on CKD Diagnosis, say "Discharge Diagnosis", and give your selection from the list. Enter reason if diagnosis is not for renal failure. B) Click on the Co-morbidity Lookup and say "Co-morbidity"; give diagnosis code, description, status choice (unknown, yes or no) and date diagnosed with that disease. If not found in Lookup, click on ICD10 Online for additional diagnoses codes.
Medications	Enter medications. Status is relative to medications on admission. Click on Lookup NS Formulary for additional information.	Say "Medications" and give details. Status is relative to medications on admission. Click on Lookup NS Formulary for additional information.
Health Status	Use drop-down menu and make selection.	Say "Health Status" and give status.
Follow-Up Plans (including Lab Data & Dialysis Order)	Use drop-down menu and type in data for each field.	Say "Lab Data on Discharge", click on Lookup Lab Tests, say your selections and give the lab results. Say "Dialysis Order" and give narrative. Say "Follow Up Plans" and give narrative.
Discharge Summary Author	Given and family names are filled in. Select title and date from drop down menus for author on discharge and attending physician.	Say "Discharge Summary Author" and give details.

OTHER –IF YOU HAVE ENTERED YOUR DATA TO THE TEMPLATE:

Saving: Click on "Save as CDA XML" button.

Viewing Your Discharge Summary: After saving the discharge summary, you will see a feedback page that will allow you to view your patient's discharge summary as done by you and as coded by hospital. Click to view those discharge records.

Linking Codes to Terminology: Each coded data element (diagnosis, laboratory) is linked to a SNOMED concept. By clicking on this highlighted code, you can explore what the code means and how it relates to other terms.

OTHER –IF YOU HAVE DICTATED YOUR DATA BASED ON THE TEMPLATE:

Viewing Your Patient's Discharge Abstract as Coded by the Hospital:
Please type in the following URL: http://www.healthinforx.ca/HealthInfoCDA/images/cihi_dischargeabstract.jpg

If you have any comments or questions please contact Grace Paterson at 494-1764 or grace.paterson@dal.ca.

Thank you for taking part in this study

Appendix D. Transcription Versus Templates Referent Tracking Analysis

There were 84 subjects that were considered for referent tracking in the 72-page patient chart. Table D.1 gives the subjects and associated chart pages that were expressed using XML-based HL7 CDA and stored along with the CKD Discharge Summaries in the Clinical Document Repository.

Table D.1 Referent Tracking of Subjects

Subject	SNOMED CT (Fully Specified)	Language Data	Referent in Chart (pages stored as HL7 CDA documents)
11816003	diet education (procedure)	1. Diet Healthy low salt/low fat 2. Time spent doing teaching č pt & wife; 3. Have review 80 NAS 80 2400 Kcal diab diet č him & given him appropriate diet information č phone # to call č questions 4. Healthy ↓fat low salt 5. Renal 80 Pro 80 Na ↓Phos 2400 Kcal Diab	1. physiciansOrders1.xml 2. progressNote1.xml 3. progressNote5.xml 4. nursingBasicCare Flow1.xml 5. nursingBasicCare Flow3.xml, nursingBasicCare Flow5.xml, nursingBasicCare Flow7.xml, nursingBasicCare Flow9.xml, nursingBasicCare Flow11.xml, nursingBasicCare Flow13.xml
103699006	patient referral to dietitian (procedure)	1. Diet: Renal Diet/diabetic/ low salt/Dietician to see 2. Diet 80 pro 80 Na ↓phos 2400 Kcal 3. Therapeutic diet Diab Heart Healthy; Goals maintain/improve labs: Alt, K, Phos, Glu. 4. Requirements: Energy: 2400 Kcals, Protein: 80 g/day. Plan to continue on 80 pro 80 Na ↓phos diet 2400 Kcals. Does not req K^+ restriction at this time.	1. physiciansOrders3.xml 2. physiciansOrders4.xml 3. nutritionScreenAnd Consult1.xml 4. nutritionScreenAnd Consult2.xml
385972005	dialysis care education (procedure)	1. Dialysis teaching session (PD,HD); 2. Time spent č pt briefly explaining CAPD and HD treatments; Long time spent talking č pt about dialysis. He has the choice of both PD & Hemo. Pt showed a CAPD bag & a cycler.	1. physiciansOrders5.xml 2. progressNote4.xml

Subject	SNOMED CT (Fully Specified)	Language Data	Referent in Chart (pages stored as HL7 CDA documents)
79301008	electrolytes measurement (procedure)	1. Labs – lytes; 2. lytes x 3 days; 3. Clinical Chemistry (Electrolytes. Item1: Sodium, Item2: Potassium, Item3: Chloride, Item4: Total CO2, Item5: Anion Gap)	1. physiciansOrders1.xml 2. physiciansOrders2.xm 3. clinicalChemistry.xml
252275004	hematology test (procedure)	1. Labs – CBC 2. The hemoglobin done on November 5 is 99. 3. Anemia Hb=101 č @ MCV/MCH will check iron study 4. General Hematology (Profile. Item 1:WBC, Item2: RBC, Item3: HGB, Item 4: HCT, Item 5: MCV, Item 6: MCH, Item 7: MCHC, Item 8: RDW, Item 9: PLT, Item 10: MPV)	1. physiciansOrders1.xml 2. clinicLetter.xml 3. progressNote4.xml 4. hematology1.xml
27171005	urinalysis (procedure)	1. Labs - Urinalysis; Bili 2. Today the urinalysis is moderate blood and 3+ protein. There are numerous hyaline casts and fine granular casts seen on microscopy. If it were not for the blood in the urine and the rapid rise this would be most consistent with diabetic nephropathy in the setting of hypertension. However, given the hematuria a glomerulonephritis needs to be ruled out. 3. U/A→small blood mild (0.3) protein, Ø casts 4. Urinalysis (Macroscopic Analysis. Item1: Colour, Item2: Appearance) (Chemical Analysis. Item1: Leukocytes, Item2: Nitrite, Item3: pH, Item4: Specific Gravity, Item5: Protein, Item6: Glucose, Item7: Ketones, Item8: Urobilinogen, Item9: Bilirubin, Item10: Blood, Item 11: Specific Gravity) (Microscopic Analysis. Item1: WBC, Item2: RBC, Item3: Epithelial Cell, Item4: Casts, Item5: Crystals, Item6: Bacteria, Item7: Yeast, Item8:	1. physiciansOrders1.xml 2. clinicLetter.xml 3. progressNotes3.xml 4. urinalysis.xml

Subject	SNOMED CT (Fully Specified)	Language Data	Referent in Chart (pages stored as HL7 CDA documents)
		Trichomonas) (Notes. Item1: hyaline casts, Item2: Finely Granular Casts)	
71878006	calcium measurement (procedure)	1. Labs – Ca 2. Followup - Ca 3. Clinical Chemistry (Routine. Item3: Calcium)	1. physiciansOrders1.xml 2. physiciansOrders6.xml 3. clinicalChemistry.xml
104866001	phosphate measurement (procedure)	1. Labs – PO4 2. Followup – PO4 3. Clinical Chemistry (Routine. Item4: Phosphorus)	1. physiciansOrders1.xml 2. physiciansOrders6.xml 3. clinicalChemistry.xml
397798009	creatine kinase measurement (procedure)	1. Labs – CK 2. CK 3. Clinical Chemistry (Enzymes. Item5:CK)	1. physiciansOrders1.xml 2. physiciansOrders4.xml 3. clinicalChemistry.xml
82962001	protein electrophoresis (procedure)	1. Labs – Albumin 2. Serum protein electrophoresis; 24 hour urine collection for Cr, protein 3. collect urine x24 h (re: Excess Hematuria) 4. A 24 hour urine was done but the results were not available. 5. Urine Volume Tests 24 Hour Urine Collection (Item1: Specimen Volume, Item2: Creatinine, Item3: Total Protein) 6. Clinical Chemistry (Routine. Item6: Albumin)	1. physiciansOrders1.xml 2. physiciansOrders2.xml 3. physiciansOrders3.xml 4. clinicalLetter.xml 5. urineVolume.xml 6. clinicalChemistry.xml
105010007	urea measurement (procedure)	1. Labs – Urea 2. BUN, 3. BUN; Followup x3 weeks with Dr. S. č urea 4. Clinical Chemistry (Routine. Item1: Urea)	1. physiciansOrders1.xml 2. physiciansOrders2.xml 3. physiciansOrders6.xml 4. clinicalChemistry.xml
86228006	uric acid measurement (procedure)	1. Labs - Uric Acid 2. Gout on allopurinol 100 uric acid ⊕ 3. Clinical Chemistry (Routine. Item5: Uric Acid)	1. physiciansOrders1.xml 2. progNotes3.xml 3. clinicalChemistry.xml
252150008	fasting lipid profile (procedure)	1. Labs – Fasting Cholesterol, LDL, HDL 2. lipid profile is satisfactory 3. ↑lipids on Lipitor 4. Lipids (Item1: Trigylcerides,	1. physiciansOrders1.xml 2. progressNote4.xml 3. pgy1Note1.xml 4. lipids1.xml

Subject	SNOMED CT (Fully Specified)	Language Data	Referent in Chart (pages stored as HL7 CDA documents)
		Tem2: Chlesterol, Item3: HDL-Cholesterol, Item4: LDL-Cholesterol, Item5: CHOL/HDL Ratio, Item6: Patient Fasting, Item7: Opacity)	
396451008	prothrombin time (procedure)	1. Labs – INR, PTT 2. Routine Coagulation (Item1: INR, Item2: PTT)	1. physiciansOrders1.xml 2. routineCoagulation. Xml
3352000	parathyroid hormone measurement (procedure)	1. ANA, ENA, TSH 2. DMHx Ø CAD Ø CVA Ø liver, lung or thyroid problems 3. Endocrinology (Thyroid Function. Item1: TSH)	1. physiciansOrders2.xml 2. pgy1Note2.xml 3. endocrinology.xml
113075003	creatinine measurement, serum (procedure)	1. Labs – Cr 2. Cr; 24 hour urine collection for Cr 3. Followup x3 week with Dr. S. č urea, Ca, PO4, lytes, creatine level 4. Renal insufficiency. Creatine by month/year 5. Clinical Chemistry (Routine. Item2: Creatinine umol/L) 6. Urine Volume Tests (Urine Collection Data. Item 2: Creatinine mmol/L, mM/TV)	1. physiciansOrders1.xml 2. physiciansOrders2.xml 3. physiciansOrders6.xml 4. pgy1Note.xml 5. clinicalChemistry.xml 6. urineVolume.xml
46511006	chloride measurement (procedure)	1. Clinical Chemistry (Electrolytes. Item 3. Chloride)	1. clinicalChemistry.xml
36048009	glucose measurement (procedure)	1. Blood chemstrip re meals and bedtime 2. His blood sugar checked daily @ home by glucocheck and fasting level range 5-6 mmol/L 3. Type II DM on OHG x 12y; well controlled HbA1c 5.8; fasting today = 8.5↑ 4. Nursing Glucose Record 5. Urinalysis (Chemical Analysis. Item6: Glucose)	1. physiciansOrders1.xml 2. progressNotes1.xml 3. pgy1Note.xml 4. nursingGlucoseRecord. xml 5. urinalysis.xml
302787001	bilirubin measurement (procedure)	1. Labs – Bili 2. Urinalysis (Chemical Analysis. Item8: Bilirubin) 3. Clinical Chemistry (Routine. Item7: Dir Bilirubin, Item8: Tot Bilirubin, Item9: Ind Bilirubin)	1. physicianOrders1.xml 2. urinalysis.xml 3. clinicalChemistry.xml

Subject	SNOMED CT (Fully Specified)	Language Data	Referent in Chart (pages stored as HL7 CDA documents)
88810008	alkaline phosphatase measurement (procedure)	1. Labs – ALP (LFT) 2. Clinical Chemistry (Enzymes. Item1: ALK Phosphatase)	1. physiciansOrders1.xml 2. clinicalChemistry.xml
69480007	gamma glutamyl transferase measurement (procedure)	1. Labs – GGT (LFT) 2. Clinical Chemistry (Enzymes. Item6: Gamma Gt)	1. physiciansOrders1.xml 2. clinicalChemistry.xml
45896001	aspartate aminotransferase measurement (procedure)	1. Labs – AST (LFT) 2. Clinical Chemistry (Enzymes. Item3: AST)	1. physiciansOrders1.xml 2. clinicalChemistry.xml
34608000	alanine aminotransferase measurement (procedure)	1. Labs – ALT (LFT) 2. Clinical Chemistry (Enzymes. Item2: ALT)	1. physiciansOrders1.xml 2. clinicalChemistry.xml
11274001	lactate dehydrogenase measurement (procedure)	1. Clinical Chemistry (Enzymes. Item4: LD)	1. clinicalChemistry.xml
489004	ferritin measurement (procedure)	1. Iron study – ferritin, sat%, TIBC 2. Special Hematology (Item1: Ferritin)	1. physiciansOrders4.xml 2. hematology2.xml
250216004	serum iron measurement (procedure)	1. Iron study – ferritin, sat%, TIBC 2. Special Hematology (Item2: Iron)	1. physiciansOrders4.xml 2. hematology2.xml
271027001	serum TIBC measurement (procedure)	1. Iron study – ferritin, sat%, TIBC 2. Special Hematology (Item3: TIBC)	1. physiciansOrders4.xml 2. hematology2.xml
165730006	transferrin saturation index (procedure)	1. Iron study – ferritin, sat%, TIBC 2. Special Hematology (Item4: Sat%)	1. physiciansOrders4.xml 2. hematology2.xml
59573005	potassium measurement (procedure)	1. Does not req. K^+ restriction at this time 2. Clinical Chemistry (Electrolytes. Item2: Potassium)	1. nutritionScreenAnd Consult2.xml 2. clinicalChemistry.xml
304383000	total protein measurement (procedure)	1. 24h urine collection for Cr, protein 2. Urine Collection Data (Item2: Total Protein)	1. physiciansOrders2.xml 2. urineVolume.xml
25197003	sodium	1. Clinical Chemistry	1. clinicalChemistry.xml

Subject	SNOMED CT (Fully Specified)	Language Data	Referent in Chart (pages stored as HL7 CDA documents)
	measurement (procedure)	(Electrolytes. Item1: Sodium)	
43396009	Hemoglobin A1c measurement (procedure)	1. Labs – HbA1C 2. Type II DM well controlled HbA1C 5.8 3. Special Hematology (Item5: Hemoglobin A1C)	1. physiciansOrders1.xml 2. pgy1note.xml 3. hematology2.xml
62889000	hepatitis B virus measurement (procedure)	1. Hepatitis B serology 2. HBV/HCV → Ø 3. Microbiology (Hepatitis B Serology Item 1: HBV Surface AG, Item2: HBV Surface AB) 4. Microbiology (Item2: HBV Surface AB)	1. physiciansOrders2.xml 2. progressNotes3.xml 3. microbiology1.xml 4. microbiology2.xml
187033005	hepatitis C virus measurement (procedure)	1. Hepatitis C serology 2. HBV/HCV → Ø 3. Microbiology (Hepatitis C Serology. Item1: HCV AB)	1. physiciansOrders2.xml 2. progressNotes3.xml 3. microbiology2.xml
314067002	autoantibody measurement (procedure)	1. ANA, ENA, antiDNA; ANCA, anti-GBM antibody 2. ENA→ Ø 3. Immunopathology (Anti-Nuclear Antibody. Item1: ANA Result) 4. Immunolopathology (Anti-DNA. Item1: ANI-DNA)(ENA Screen. Item1: ENA Screen)(Anti-Myeloperoxidase. Item1: Anti-MPO)(Ani-Proteinase 3. Item 1: Anti-PR3) 5. Immunopathology (Anti-Glomerular Basement Membrane Antibody. Item1: Anti-GBM)	1. physicianOrders2.xml 2. progressNotes3.xml 3. immunopathology1.xml 4. immunopathology2.xml 5. immunopathology3.xml
2220009	complement component assay (procedure)	1. C3, C4 2. Complements ⊕ 3. Immunology (Complements. Item1: Complement C3, Item2: Complement C4)(Item3: Cryoglobulin RT)	1. physicianOrders2.xml 2. progressNotes3.xml 3. immunology.xml
166804009	electrophoresis: albumin (procedure)	1. Labs – albumin 2. Clinical Chemistry (Routine. Item6: Albumin)	1. physiciansOrders1.xml 2. clinicalChemistry.xml
68088000	acebutolol (product)	1. acebutolol 200 mg po BID 2. ↑acebutolol to 400 mg po BID (from today)	1. physiciansOrders1.xml 2. physiciansOrders4.xml 3. physiciansOrders5.xml

Subject	SNOMED CT (Fully Specified)	Language Data	Referent in Chart (pages stored as HL7 CDA documents)
		3. acebutolol 200 mg po BID 4. acebutolol 200x2 4. HTN x 15yr acebutolol 200 mg 5. will ↑ Acebutolol 400to 400x2 6. will control BP č ↑ acebutolol 7. Acebutolol 200 mg po BID 8. Medication Record/7 Day Acebutolol 200 mg 9. Medication Record/7 Day Acebutolol 200 mg 10. Medication Record/7 Day Acebutolol 400 mg 11. Acebutolol 300 mg BID 12. Meds include acebutolol	4. progressNote2.xml 5. pgy1Note1.xml 6. clinicalLetter2.xml 7. progressNote3.xml 8. dischargeMedication Form4.xml 9. medicationRecord7Day 2.xml 10. medicationRecord7 Day3.xml 10. medicationRecord7 Day4.xml 11. nursingAssessment1. xml 12. nutritionScreenAnd Consult2.xml
25246002	allopurinol (product)	1. allopurinol 100 mg po OD 2. Gout dx 2 yrs ago on allopurinol 100 mg OD; allopurinol 100x1 3. allopurinol 100 mg once a day 4. Gout on allopurinol 100 OD 5. Allopurinol 100 mg po OD. 6. Allopurinol 100 mg po OD 7. Allopurinol 200 mg OD 8. Meds include allopurinol	1. physiciansOrders1.xml 2. progressNote2.xml 3. clinicalLetter2.xml 4. pgy1Note3.xml 5. dischargeMedication Form6.xml 6. medicationRecord7Day 2.xml 7. nursingAssessment1. xml 8. nutritionScreenAnd Consult2.xml
80870001	glyburide (product)	1. glyburide 5 mg po BID 2. type II DM x12 yr was on metformin +glyburide but metformin D/C 2/52 ago by his GP. Now taking only glyburide 5 mg x2 3. glyburide 5x2 4. glyburide 5 mg b.i.d. 5. Type II DM on OHG 6. glyburide 5 mg po BID 7. glyburide 5 mg po BID 8. glyburide 5 mg bid 9. Meds include glyburide	1. physiciansOrders1.xml 2. progressNote1.xml 3. progressNote2.xml 4. clinicalLetter2.xml 5. pgy1Note3.xml 6. dischargeMedication Form4.xml 7. medicationRecord7Day 2.xml 8. nursingAssessment1. xml 9. nutritionScreenAnd Consult2.xml
7947003	aspirin (product)	1. Hold ASA 2. ECASA 325 mg po OD 3. ECASA 325 x1	1. physiciansOrders1.xml 2. physiciansOrders5.xml 3. progressNote2.xml

Subject	SNOMED CT (Fully Specified)	Language Data	Referent in Chart (pages stored as HL7 CDA documents)
		4. 325 mg of Aspirin a day 5. ECASA 325 mg po OD 6. ECASA HOLD 7. ECASA 325 mg po OD 8. ECASA 325 mg OD	4. clinicalLetter2.xml 5. dischargeMedication Form4.xml 6. medicationRecord7Day 1.xml 7. medicationRecord7Day 4.xml 8. nursingAssessment1. Xml
59941008	Diltiazem (product)	1. Cardizem SR 180 mg po bid (start tonight) 2. Ditiazem HCI Cap CR 90 mg (SR) Rx:**New_Order-1** with Atorvastatin Calcium. 3. Diltiazem SR 180 mg po BID 4. Cardizem SR 180 mg po BID	1. physiciansOrders5.xml 2. drugInteractions Warning.xml 3. dischargeMedication Form7.xml 4. medicationRecord7Day 3.xml
71724000	ferrous sulfate (product)	1. FeSO4 600 mg po qhs x 1 week then 900 mg po qhs 2. FeSO4 900 mg po OD 3. FeSO4 600 mg po qhs; FeSO4 900 mg po qhs	1. physiciansOrders5.xml 2. dischargeMedication Form7.xml 3. medicationRecord7Day 4.xml
129484001	terazosin (product)	1. Hytrin 2 mg po qhs 2. Hytrin 2 mg po qhs 3. Hytrin 2 mg po qhs	1. physiciansOrders5.xml 2. dischargeMedication Form1.xml 3. medicationRecord7Day 3.xml
81609008	furosemide (product)	1. Lasix 40 mg po OD 2. HTN x 15yr on Lasix 40 3. Lasix 40 mg once a day 4. Lasix 40 mg po OD 5. Lasix 40 mg po OD 6. Lasix 40 mg OD 7. Meds include Lasix	1. physiciansOrders1.xml 2. progressNote2.xml 3. clinicalLetter2.xml 4. dischargeMedication Form3.xml 5. medicationRecord7Day 1.xml 6. nursingAssessment1. Xml 7. nutritionScreenAnd Consult2.xml
108600003	Atorvastatin (product)	1. Lipitor 20 mg po OD 2. Diltiazem HCI Cap CR 90 mg (SR) Rx:**New_Order-1** with Atorvastatin Calcium 3. ↑lipids on Lipitor 20 OD; lipitor 20x1 4. Lipitor 20 mg once a day	1. physiciansOrders1.xml 2. drugInteractionWarning .xml 3. progressNote2.xml 4. clinicLetter2.xml 5. dischargeMedication Form3.xml

Subject	SNOMED CT (Fully Specified)	Language Data	Referent in Chart (pages stored as HL7 CDA documents)
		5. Lipitor 20 mg po OD 6. Lipitor 20 mg po OD 7. Lipitor 20 mg OD 8. Meds include Lipitor	6. medicationRecord7Day 1.xml 7. nursingAssessment1. Xml 8. nutritionScreenAnd Consult2.xml
108537001	amlodipine (product)	1. Norvasc 10 mg po OD 2. D/C Norvasc 3. HTN x 15yr on Norvasc 5 mg ↑ 2 wks ago to 10 mg 4. Norvasc 10 once a day 5. Norvasc 10 mg po OD	1. physiciansOrders1.xml 2. physiciansOrders5.xml 3. progressNote2.xml 4. clinicLetter2.xml 5. medicationRecord7Day 1.xml
55217007	calcium carbonate (product)	1. Tums 1 po č each meal 2. TUMs 1x3 3. Tums one with each meal 4. on NaHCO3|Tum|Albee +C 5. Tums taken č each meal 6. Tums taken č each meal	1. physiciansOrders2.xml 2. progressNote2.xml 3. clinicLetter2.xml 4. progressNote3.xml 5. dischargeMedication Form4.xml 6. medicationRecord7Day 2.xml
57376006	sodium bicarbonate (product)	1. sodium bicarbonate 1.0 g po bid 2. on NaHCO3|Tum|Albee +C 3. NaHCO3 1 g po BID 4. Sodium Bicarbonate 1.0g po BID	1. physiciansOrders3.xml 2. progressNote3.xml 3. dischargeMedication Form5.xml 4. medicationRecord7Day 2.xml
412581007	vitamin B complex + vitamin C (product)	1. Albee č C po OD 2. Albe + C 1 po OD 3. Albee č C taken	1. physiciansOrders3.xml 2. dischargeMedication Form1.xml 3. medicationRecord7Day 2.xml
413672003	blood test requested (context-dependent category)	1. Followup	1. physiciansOrders6.xml
80274001	glomerular filtration rate (observable entity)	1. The calculated creatinine clearance had a creatinine of 462 with 18 mil/min	1. clinicalLetter.xml
5880005	physical examination procedure (procedure)	1. Review of systems 2. O/E rd ♂; not in distress; Ø L-L edema; Ø rash; Ø clubbing; Ø lymphadenopathy; chest clear, ENT ok; CVS S1+S2+O; Abd	1. progressNote2.xml 2. progressNote3.xml

Subject	SNOMED CT (Fully Specified)	Language Data	Referent in Chart (pages stored as HL7 CDA documents)
		soft + lax + not tender Ø renal bruit; CNS Ø focal deficit; reflex v ; lower limb sensation OK	
7246002	kidney biopsy (procedure)	1. Renal insufficiency for investigation including Kidney Bx 2. Radiology – Post Renal Biopsy 3. 69 y.o. ♂ admitted for investigation of renal function decline and for possible kidney Bx 4. admitted to the hospital for further serological testing and renal biopsy 5. Had biopsy today 6. Kidney, Needle Biopsy 7. Biopsy – advance nephrosclerosis	1. physiciansOrders1.xml 2. physiciansOrders3.xml 3. progressNote1.xml 4. clinicLetter2.xml 5. nutritionScreenAndConsult2.xml 6. surgicalPathologyReport2.xml 7. progressNotes4.xml
165994006	sample serology (procedure)	1. all serology negative 2. Hepatitis B Serology. HBV Surface AG; HBV Surface AB	1. progressNote4.xml 2. microbiology1.xml
265764009	renal dialysis (procedure)	1. Patient teaching about CAPD and hemodialysis. Patient to choose modality and then will be booked for access placement.	1. progressNotes4.xml
277667006	ultrasound guided biopsy (procedure)	1. Ultrasound guided renal biopsy	1. patientDiagnosticImaging.xml
127013003	diabetic renal disease (disorder)	1. Most likely baseline disease, diabetic nephropathy complicated by other active process 2. If it were not for the blood in the urine and the rapid rise this would be most consistent with diabetic nephropathy in the setting of hypertension.	1. progressNotes2.xml 2. clinicLetter2.xml
108333003	smoking/drinking /substance abuse habits (navigational concept)	1. He quit smoking 15 years ago after a 30 pack year history	1. clinicLetter2.xml
160476009	social / personal history observable (observable entity)	1. Marital status	1. inpatientAdmissionForm1.xml
313424005	at risk of disease	1. The risk of myopathy and rhabdomyolysis may be increased	1.

Subject	SNOMED CT (Fully Specified)	Language Data	Referent in Chart (pages stored as HL7 CDA documents)
	(finding)	by co-administration of Artovastatin Calcium Tab 20mg and Diltiazem HCl Cap CR 90mg (SR).	drugInteractionWarnings.xml
406221003	health status (observable entity)	1. not in distress 2. Perception of health status/reason for coming to hospital: ↑ creat. Bx	1. physicianOrder1.xml 2. patientAdmissionAssessment1.xml

Appendix E. Consent Form For Patient Portal Study

Consent form for patients invited into Phases 2 & 3 of the study

[letterhead]

Patient Informed Consent Form

Study Title:	**HealthInfoRx™: Lifelong Learning for Chronic Disease Patients and Health Care Providers**
Principal Investigators:	Dr. David Zitner, Grace Paterson, Dr. John Ginn Dalhousie University, Division of Medical Informatics L5 Tupper Building, 5849 University Avenue Halifax, NS B3H 4H7
Associate Investigators:	Dr. Desmond Leddin, Gastroenterology Department, QEII HSC Dr. Donald MacIntosh, IBD Specialty Clinic, QEII HSC Simuplex Inc., Toronto, Ontario
Study Sponsor:	Office of Learning Technologies Human Resources Development Canada

Introduction:

You are invited to take part in a research study at Dalhousie University. Taking part in this study is voluntary. The quality of your health care will not be affected by whether you participate or not. Participating in this study might not benefit you, but information may be gained that will benefit others. You may withdraw from the study at any time without affecting your care. The study is described below. This description tells you about the risks, inconvenience, or discomfort that you might experience. You should discuss any questions you have about this study with the people who explain it to you.

Purpose of the study

We are trying to develop an Internet website that will allow patients with chronic diseases to gain access to information about their condition and to communicate with their healthcare providers. We plan to develop an initial prototype that will be pilot tested by patients with IBD and then test the usefulness and effectiveness of a prototype over a one-year period.

Who can participate in this study?

Patients have been randomly selected by a computer program to receive this letter of invitation to take part. You may take part in this study if you have access to the Internet and are a patient with the Specialty IBD Clinic in Halifax, NS.

Procedures of the study

There are four phases to this study.
Phase 1: In this phase, you will take part in a focus group along with other IBD patients. In this focus group, you will be asked questions about what you think a web-site offering information and education about IBD should look like. Patients who agree to take part in the focus group session will meet with other patients and a facilitator to discuss the website and what information you, as patients, need to be able to access. The focus groups will take about 2 hours. With your permission, the focus group session will be audiotaped so that we have a complete record of responses. Only the research study staff and investigators will have access to the taped session. Participation is voluntary.

You will also be asked to complete a short questionnaire about use of the Internet in order to confirm your ability to participate in the other phases of the study. Once this is done, you will be asked to complete a set of questionnaires about your overall health, knowledge of IBD, diet, prevention and management activities you do, and some general questions about the current information you receive about your condition.

Phase 2: In this phase, you will be asked to go on-line and use the web-site for one month. At the beginning, you will be taught how to get to the site, and how to get around it. At the end of this initial pilot test, you will be asked to provide feedback on the web-site by completing an on-line survey. You will be asked questions about the actual lay-out of the site such as how easy it was to access and use, how you found moving around the site, etc.

Phase 3: After we have made changes to the site that you suggested at the end of phase 2, you will be asked to continue to use the web-site for a period of about 11 months. We will ask you at different times to answer some questions about your use of the site (similar to the questions in phase 2). At the end of this longer test of the web-site, you will be asked to complete the same questionnaires from phase 1.

Following this, the researchers will provide a summary of the results of the testing of the web-site.

Risks and discomforts

You may find the questionnaires you receive during the course of the study upsetting or distressing or you may not like all the questions that you will be asked. You do not have to answer those questions you do not wish to. If at any time during the study, you have feelings you wish to speak with someone about, there will be a healthcare professional available for you to see.

Possible benefits

There is no guarantee you will benefit personally by taking part in this study. However, information may be gained that will help in the treatment of patients with similar disease in the future.

Compensation

There will be no costs to you for being in the study, nor will you be paid for participating in the study.

Confidentiality

You will not be identified as a study participant in any reports or publications of this research. Your records will be kept in a secure area such as a locked file cabinet. Only the staff involved in the research study will see them. With your permission, your family doctor will be informed of your participation in this research study.

Declaration of financial interest

HealthInfoRx™ has been developed by Health Informatics at Dalhousie University, therefore, there are proprietary rights as well as possible future financial rights held by Medical Informatics, including the principal investigators. The private sector partner on this study, Simuplex, Inc. has licensing rights to the e-learning software and web portal design.

Withdrawal from the study

If you choose to participate and later decide to change your mind, you can say no and stop the research at any time. A decision to stop being in the study will not affect your health care.

Other pertinent information

As part of the final web-site, we would like to be able to offer patients and rural primary health care workers the opportunity to consult with the specialists at the IBD clinic about their own or their patients' condition. Therefore, part of what we plan to do during this initial testing of the web-site is to develop this additional piece. We may ask you, during this study to provide feedback on the usefulness of being able to consult with the IBD clinic through a password secured section of the web-site. This section will be only be able to be used by those patients and health care workers given a user ID and password. In this way, no one else will be able to see any personal information.

You will be told about any new information that might affect your decision about being in this research study. You will be provided with a copy of this consent form for your own records.

Questions or Problems

If you have any questions about the study, you should contact [name of person, address, 24-hr contact number, email]. If you have any questions about your rights as a research participant, you should first contact the principal investigator, [name]. If any questions remain following this, you should contact the Patient Representative at 473-2133 (VG site) or 473-2880 (CHMC site).

Signatures

I have read the explanation about this study. I have been given the opportunity to discuss it and my questions have been answered to my satisfaction. I hereby consent to take part in phases 2 and 3 of this study, including completing the questionnaires at various points during the study.

____

Signature of Participant   Date Signed

____

Signature of Person Conducting Consent Discussion   Date Signed

____

Signature of Witness   Date Signed

____

Signature of Investigator   Date Signed